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ABSTRACT

The book explores the legal profession's role in protecting the rights of mentally handicapped individuals. Section 1 provides background on mental retardation and residential care, explaining that mental retardation and poverty are closely interrelated. Section 2 reviews the long accepted public policy of supplanting institutional care with community based alternatives. Section 3 details legal assistance approaches, including class actions, individual representation, and legislative advocacy. Barriers to access of institutionalized clients, such as conflicts of interest between a mentally retarded and his/her guardian, and advocacy projects are considered in the fourth section. The final section discusses resources and priorities for the future. A questionnaire on legal advocacy for mentally retarded persons and the results of responses from 100 members of the legal professions are appended. (PHR)

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THE NEW CLIENTS
LEGAL SERVICES FOR MENTALLY RETARDED PERSONS

by STANLEY S. HERR*

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The New Clients:

Legal Services for Mentally Retarded Persons

by Stanley S. Herr

I. INTRODUCTION

To be assigned the label "mentally retarded" is to face a massive stigma and a massive legal risk. The person so labelled can be mistakenly viewed as being devoid of competence. No other disability imposes so many risks of sub-human treatment.

The risks are not hypothetical. There is the legal risk of being excluded from schools and being banished to institutions, the risk of being saddled with legal disabilities unwarranted by your particular abilities, the risk of having nowhere to live other than the back-ward of a massive state institution. And there is the overarching risk of having no advocate or no forum in which to complain of this. In short, to be labelled "mentally retarded" is to be a victim of prejudices which threaten life, self-esteem and safety.1/

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1. A Florida legislator publicly proposed a "euthanasia" statute for children with Down's Syndrome and others in institutions for the retarded. A young retarded girl wrote him the following letter:

> Dear Dr. Sackett,
>
> My name is Amy, I am 10 years old and go sylvania Heights Elementary in miami. I was born with Down's Syndrome, clubfeet, and Problems breathing. my parents took good care of me and now I can run and talk and play. I love my family and they love me a whole lot. Please don't do anything to hurt other people like me. I am a person just like you.
>
> Love Amy Plotkin.

In 1979, several hundred residents of mental retardation facilities will die avoidable deaths. Some will perish by asphyxiation on wards without adequate supervision. Some will be scalded to death, and some will be beaten. Many will be the victims of inadequate medical care. By causes too numerous to recite, lives will be shamefully foreshortened -- in ends often grotesque and sometimes brutal. Others will survive assault or injuries, maimed and scarred.2/

Even for those who suffer no outward physical abuse, institutionalization will exact a toll of mutilated spirits no less real and detectable. If self-respect is as John Rawls termed it, "the main primary good,"3/ custodial institutions - a symbol of inferior status - do grievous harm to this most basic aspect of personality. The debilitating effects of a damaged identity, as social scientists show, are long-lasting, "causing the victim to suppress aspirations that look unattainable when seen with the restricted vision imposed by a withered self-concept."4/

The harm imposed by such institutional segregation is more than psychological. Those deprived of training or activity will develop stereotyped,

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2. See, e.g., Halderman v. Pennhurst State School, 446 F. Supp. 1295, 1308-10 (E.D. Pa. 1977); Wyatt v. Stickney, 344 F. Supp. 387, 393-4, n. 13, (M.D. Ala. 1972):

> (a) a resident was scalded to death by hydrant water; (b) a resident was restrained in a strait jacket for nine years in order to prevent hand and finger sucking; (c) a resident was inappropriately confined in seclusion for a period of years, and (d) a resident died from the insertion by another resident of a running water hose into his rectum. Each of these incidents could have been avoided had adequate staff and facilities been available.

3. J. Rawls, A Theory of Justice 534 (1971).

4. Karst, Foreword: "Equal Citizenship Under the Fourteenth Amendment," 91 Harv. L. Rev. 1,7 (1977). For thorough discussion of legal responses to custodial treatment, see Symposium: "Legal Services for Mentally Retarded Persons," 31 Stanford L. Rev. No.4 (in press 1979).

bizarre or even menacing behavior. Residents are thus condemned to a self-fulfilling prophecy of dependency and danger. Those denied physical therapy or exercise will suffer terrible contractures and shrivelled limbs.

One proposition commands almost universal consensus. There are just too few advocates to reach more than a minuscule fraction of those in mental institutions far removed from the rest of society. The legal services community and the legal profession must allocate specific resources to redress this isolation, neglect and abandonment. In interview after interview, questionnaire after questionnaire, conference after conference, knowledgeable people have echoed variations on this theme.5/ Neither a free market model nor a political model will produce an equitable distribution of legal services for the mentally disabled. Those without votes, without funds they control, without voices that can be heard in legal services board rooms remain shut off from access to justice. To reach them, and to serve "the ends of justice" their advocates must hurdle more than "an economic barrier to adequate legal counsel."6/

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5. See, e.g., Questionnaire response from Murray Bernstein, Attorney-Supervisor, Mental Hygiene Bureau, Legal Aid Society, New York City: "The volume of requests for assistance, especially from those in institutions, is just too great for the very few people involved in this area."

6. Legal Services Corporation Act Amendments of 1977, 42 U.S.C. 2996(3).

A. The Context

1. Emerging Issues

Until recent years, the public and the legal profession paid virtually no attention to the legal rights of persons in retardation institutions.[7] In theory, such persons had the same basic rights as others. In practice, their rights could be abrogated without due process or searching inquiry into the individual's specific abilities and disabilities. In theory, living in an institution impaired no civil right and offered but one of a spectrum of residential alternatives. In practice, institutional assignment was treated as tantamount to mental incompetency, and alternatives simply were not canvassed or created. In theory, the purpose of the institution was to habilitate and train the resident in preparation for an eventual return to the community. In practice, the massive institution was a custodial dead end. The deprivations imposed were de facto, not de jure, a reflection of the institution's limitations, not the residents'.

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7. Professor Gunnar Dybwad of Brandeis University, formerly Executive Director of the National Association for Retarded Citizens, was a lonely pioneer in this field. See, e.g., G. Dybwad, "Comments on the Legal Status of the Mentally Retarded in the U.S." (NARC Memorandum to the International League of Societies for the Mentally Handicapped, March 1, 1961) (unpublished, in files of author); G. Dybwad, "The Undeveloped Resource at the Edge of Change" (Paper presented at the American Association on Mental Deficiency, San Francisco, November 15, 1968):

> This whole concept that the mentally retarded have basic human rights, and, furthermore, that these human rights could be enforced, is a very new one, but it is coming. At various times I have urged administrators of state programs to read carefully the "signs on the wall" before they become subject to emanating judicial interference.

For advocates for retarded citizens, the quality and nature of residential services is at the cutting edge of change.8/ By representing residents or those at risk of committal or recommittal to custodial facilities, advocates can challenge distorted service patterns which swell the institutions and thwart community alternatives. Instead, they can seek aid for retarded persons within intact families, durable family substitutes or small family-scaled group living arrangements. Residential issues, of course, are not the sole concern of retarded clients; education, employment, guardianship, governmental benefits and non-discrimination are among their other compelling concerns. Lawyers can work to increase the range and quality of the choices available to their clients and can reinforce the consumer coalitions which seek to end the destructive segregation of the disabled.

The large public institution is a conspicuous monument to a legacy of misunderstanding. Consider a parallel drawn from the treatment of blind persons. Historically, blind persons were sent to remote residential state schools as a virtual pre-condition for the receipt of public educational services. The blind, like the retarded, were deemed to be better off among themselves and "protected" from the risks of community living.9/ With laws

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8. Menolascino, "Introduction," National Association for Retarded Citizens, A National Forum on Residential Services, (New Orleans, December, 1976) at 2: "The issue of residential services is, without question, the key one in the field of mental retardation in our country today. From the viewpoints ...of retarded citizens, their advocates, public officials and the financial-political repercussions -- every other issue in this area pales by comparision."

9. See generally, tenBroek and Matson, "The Disabled and the Law of Welfare," 54 Cal. L. Rev. 809 (1966) on the "custodializing features" of public welfare programs for the disabled. See, e.g., McCrocklin, Building Citizenship 244 (1961):

> "The blind, the deaf, the dumb, the crippled, and the insane and feebleminded are sometimes known collectively as the defectives -- people who are lacking some normal faculty or power. Such people often need to be placed in some special institution in order to receive proper attention."

now requiring special instruction and services in schools and agencies close to home, that costly mistake is being rectified.

It is well past time to phase down - and phase out - large institutions for the retarded and the model of containment they imply. In journals,[10] conferences,[11] legislative hearings[12] and courts,[13] a long line of clients, consumer representatives and distinguished professionals has been telling us that the day of the institution is past. It will not, however, fall of its own weight. Quite the contrary, there is a backlash to preserve the institution's "brick and mortar" sense of security. While policy statements and court pronouncements laud community-based care, the bulk of Federal and state mental retardation budgets still goes to institutions. Against heartening evidence of progress, the hazards of dumping and complacency remain.

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10. See Herr, "Civil Rights, Uncivil Asylums and the Retarded," 43 Cin. L. Rev. 679, 780 (1974); Mason & Menolascino, "The Right to Treatment for Mentally Retarded Citizens: An Evolving Legal and Scientific Interface," 10 Creighton L. Rev. 124 (1976); W. Wolfensberger, "The Origin and Nature of Our Institutional Models," in President's Committee on Mental Retardation, Changing Patterns in Residential Services for the Mentally Retarded 70-75 (2nd ed. 1976).

11. National Association for Retarded Citizens, a National Forum on Residential Services, New Orleans, December 3-4, 1976, "Summary and Trends" at 180, 187-189; International League of Societies for the Mentally Handicapped, Improving the Quality of Life: A Symposium on Normalization and Integration (Airlie House, Virginia, August 17-20, 1976) "Shifting Empires" 17-19.

12. See, e.g., Civil Rights of Institutionalized Persons: Hearings Before the Subcommittee on the Constitution of the U.S. Senate Committee of the Judiciary on S. 1393, 95th Cong., 1st Sess. (1977) at 27-79, 198-202.

13. See, e.g., Wyatt v. Stickney, 344 F. Supp. 373 and 387 (M.D. Ala. 1972), aff'd sub. nom, Wyatt v. Aderholt, 503 F. 2d 1305 (5th Cir. 1974); Davis v. Watkins, 384 F. Supp. 1196 (N.D. Ohio 1974); Welsch v. Likins, 373 F. Supp. 487 (D. Minn. 1974) and No. 4-72-Civ. 451 (D. Minn. October 1, 1974) New York State Association for Retarded Children and Parisi v. Rockefeller, 357 F. Supp. 752 (E.D.N.Y. 1973); NYSARC and Parisi v. Carey, No. 72-C-356/357 (E.D.N.Y., April 30, 1975), approved 393 F. Supp. 715 (E.D.N.Y. 1975); Halderman v. Pennhurst State School, 446 F. Supp. 1295 (E.D. 1977).

2. Legal Interest in Residents' Rights

This book explores the legal profession's role in protecting the rights of persons facing institutional or "deinstitutional" placement. For those unfamiliar with the field, Section I provides background on mental retardation and residential care. Section II reviews a long-accepted public policy to supplant institutional care with community-based alternatives. Section III details various legal assistance approaches. Section IV raises issues of obtaining access to institutionalized clients. The concluding section discusses resources and priorities for the future.

The legal profession has an important, but little explored, stake in protecting the rights of persons with retarded mental development. Retarded citizens have legal problems common to the poor and the public at large. In addition, some are eligible for special benefits or are exposed to problems of discrimination. Until recently, for example, school exclusions and conditions in "treatment" institutions were overlooked as fields of lawyer work. Due to their disabilities, dependence or isolation, retarded persons were not likely to visit a law office, write a letter or telephone a lawyer. And many lawyers, not trained to recognize or assist disabled persons, failed to reach out or make inquiries.

As this study demonstrates, lawyers have begun to share their skills with individuals and organizations asserting the rights of retarded people. This movement remains in an embryonic and pioneering stage. The elements are at hand for real progress: new clients with desperate needs and new laws and advocacy resources with untested potential. Yet, except in a few states and locales, the legal advocate of a retarded client is an unfamiliar figure treading unfamiliar terrain.

B. The Mental Retardation Landscape

1. Terminology

Lawyers venturing into the mental disability field face the pitfalls of statutory and nosological categories insensitive to subtle human differences. The categories used often reflect outmoded classifications and conceptualizations. Mental defective, retardate, mental subnormal, moron, idiot, imbecile and the like are now generally regarded as pejorative terms. One day mentally retarded may be added to that list, as better ways are found of describing concrete human needs. In place of categorical, all-embracing statutory definitions, legal regulation could define needs for particular types of services or resources. For what we now -- with apologies for the shorthand -- refer to as mental retardation is in reality a highly variable, relative and differentiated condition.

2. What is mental retardation?

Mental retardation is a social construct, not a single clinical entity. The term has no precise or absolute meaning, and there is considerable disagreement as to its upper margin. "Mental retardation," as defined by the American Association on Mental Deficiency, "refers to significantly subaverage intellectual functioning, existing concurrently with deficits in adaptive behavior, and manifested during the developmental period."14/ In plain English, a mechanistic interpretation reduces this definition to three elements: a label applied to a person who scores below 97% of the population on standardized intelligence tests, who also lacks the social skills to cope with his/her particular environment, and who also has been recognized as having had those problems of adaptive behavior since childhood or early adolescence.

Several controversies swirl around this broad definitional territory. Contention surrounds the standards of measured intelligence applied, the peer group against which norms of adaptive behavior are developed and the arbitrary statistical incidence figure assumed. Cultural bias may also be present in the assumption that the tested person has had opportunities to develop, learn and absorb a culture and language similiar to those enjoyed by the sample upon whom the test was standardized.15/

Lawyers should be skeptical of the processes by which their clients are classified as mentally retarded. They should challenge categorical assumptions that persons so labelled can be denied their legal or human rights or be treated in ways fundamentally different in kind from their peers and neighbors.

3. Prevalence Rates and Labelling Games

In 1965, The World Health Organization recommended a five-tier categorization system: degrees of retardation being classified as borderline, mild,

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14. American Association on Mental Deficiency, Manual on Terminology and Classification in Mental Retardation 5 (H. Grossman rev. ed. 1977).

15. See J. Mercer, Labeling the Mentally Retarded (1973); Larry P. v. Riles, 342 F. Supp. 1306, (N.D. Cal. 1972), aff'd, 502 F. 2d 963 (9th Cir. 1974).

moderate, severe and profound.16/ Less than three years later a WHO Expert Committee effectively redrew and narrowed the definition of mental retardation by urging deletion of the borderline group; e.g. the classification of those with I.Q. scales of about 68-85 as "borderline mentally retarded."17/ Thus, at a stroke, 13% of the world's population were deemed outside the scope of mental retardation definitions or services. Putting aside those borderline cases, the WHO Fifteenth Report observed that "rates found up to now indicate that 1-3% of the population are mentally retarded."18/

In the United States, over 6 million people are mentally retarded. This commonly quoted prevalence estimate is based upon a 3% incidence figure and an I.Q. cutoff of about 67.19/ It can not be overemphasized in this test ridden society that neither I.Q. scores, nor indeed any test, can measure directly the genetically inherited potentialities of a person. Any test at best indicates how a person performed in a certain testing situation and how some potentialities are developed and expressed in a specific environment.20/

Erasing unhappy labels will not erase the unhappy experience facing the "obviously" handicapped or socio-economically disadvantaged. When, however, the label itself becomes one of the grounds for discrimination and committal to segregated facilities, there is reason for special scrutiny.

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16. World Health Organization (WHO), Manual of the International Statistical Classification of Diseases, Injuries and Causes of Death, 1965 revision (Geneva 1967); category 310, at 154-155.

17. WHO, Organization of Services for the Mentally Retarded, Fifteenth Report of The Who Expert Committee on Mental Health (WHO Technical report series, 392 (Geneva 1968) at 11.

18. Id. at 6-7.

19. U.S. Dept. of H.E.W., The Problem of Mental Retardation at 5. (DHEW Pub. No. (OS) 72-25).

20. See generally, C. Senna, et. al., The Fallacy of IQ (1973), J. Mercer, Labeling the Mentally Retarded (1973); O. Klineberg, Negro Intelligence and Selective Migration (1935); E. Zigler, The Future of Social Policy for Children 7 (Center on Human Policy, 1973).

4. Institutions

The term "institution," equally imprecise, has come to refer to large residential facilities segregating mentally retarded persons and those with cerebral palsy and related conditions from the rest of society. A total institution, as classically defined, is "a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life."21/ The American Association on Mental Deficiency provides a substantially similar definition: "an institution is a public or private facility or building(s) providing a constellation of professional services . . . on a 24-hour residential basis including those directed toward the care, treatment, habilitation, and rehabilitation of the mentally retarded and has traditionally been separated from the general population."22/ By these definitions, well over a quarter of a million Americans are trapped in institutions which restrict elements of choice, limit interaction with outsiders and fuse the place of residence with the place of work, recreation and all other activity.

Mounting evidence shows that institutions provide a strikingly lower quality of life for disabled people than do group homes or hostels.23/ Over 93% of the 1705 institutions for the mentally handicapped currently

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21. E. Goffman, Asylums xiii (1961).

22. A.A.M.D. Manual, supra note 14.

23. G.S. Baroff, Mental Retardation: Nature, Causes and Management 352, 401 (1974). Glenn, "The Least Restrictive Alternative in Residential Care and the Principles of Normalization," in President's Comm. on Mental Retardation, The Mentally Retarded Citizen and the Law, 499, 514 (1976). R. King, N. Raynes & J. Tizard, Patterns of Residential Care: Sociological Studies in Institutions for Handicapped Children (1971).

functioning are not accredited by any professional organization.24/ An estimated 176,000 persons are housed in 246 state institutions for the mentally retarded, typically the largest and most inferior facilities.25/ Empirical studies demonstrated that when retarded children were transferred from institutions to good environmental conditions, those children made impressive developmental gains as compared to a control group of children who remained in the institution.26/ Moreover, those same persons as adults became integrated members of their community.27/ The testimony of leading national experts, typified by that of the Executive Director of the National Association for Retarded Citizens, similarly points to the debilitating and destructive effects of institutionalization:

> generally institutions are less able to help the retarded develop than are homes. The longer persons are institutionalized, the more their cognitive, social and behavioral development is destroyed. They lose their spontaneity. They show increased dependency. They develop negative attitudes toward themselves. Their mental development is further retarded. They show an increase in self-stimulative behavior and a propensity to injure themselves. Their physical growth is stunted; and their language development is reduced.28/

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24. U.S. Dept. of Health, Education and Welfare, Survey of Institutional Persons, Table No. 68, Type and Size of Facility by Accreditation by Organization (unpublished survey, 1977).

25. President's Committee on Mental Retardation, (hereinafter P.C.M.R.), Mental Retardation: Trends in State Services (DHEW No. (OHD) 76-21014) at 31; President's Committee on Mental Retardation, Mental Retardation: The Known and the Unknown (DHEW No. (OHD) 76-21008) at 66.

26. Skodal and Skeels, "A Final Followup of One Hundred Adopted Children," 75 J. of Genetic Psychology 85 (1949).

27. Skeels, Adult Status of Children with Contrasting Life Experiences, Monograph 31 Society for Research in Child Development No. 3, (University of Chicago Press, 1966).

28. Record, Vol. 1, at 151, Testimony of Dr. Philip Ross, Halderman v. Pennhurst State School Hospital, 446 F. Supp. 1295 (E.D. Pa. 1977).

5. Homes in the Community

For every person in an institution for the retarded, there are some thirty retarded persons living in ordinary neighborhoods. The vast majority live independently or with their families and hold jobs or attend community schools. For the most part, they are integrated with their non-handicapped peers. Those with more severe disabilities may require certain forms of special assistance, including residential services. In some parts of the country, the spectrum of residential alternatives now includes foster care, group homes, semi-supervised apartment living, nursing homes and other institutions.[29] Decent alternatives and comprehensive community support systems are still sorely lacking.

It is a common fallacy that a line can be drawn dividing those who can live in some community based setting from those in institutions. There is no such line. In some catchment areas, the creation of networks of alternative residential and day services has eliminated the use of institutions. Those areas serve as reminders that there are viable options to institutionalization or dumping of former residents.

C. Civil Rights Perspectives

1. Poverty and Mental Retardation

Mental retardation produces poverty, and poverty produces mental retardation. A wide variety of studies, examining cultural as well as biosocial factors, finds an inverse correlation between retardation rate and economic level.30/ It has been suggested that, if the same rates of retardation found among middle class families were distributed among all classes, the incidence of retardation would drop by some 80%.31/ Even allowing for cultural bias in the instruments used to measure intelligence, the poor - through exposure to unhealthy physical environments, deficient medical services, lead poisoning - run a greater risk than others of real or apparent retarded mental development. Mental retardation then reflects the cumulative burden of inequitable distribution of services and life chances.

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[29] See, e.g., Glenn, supra note 23, at 512-14, C. Cherrington & G. Dybwad (eds.), New Neighbors: Retarded Citizens in Quest of a Home (1974). In California, over 5000 retarded persons were served in foster homes, while nationally, 474 group homes for the retarded were in operation. P.C.M.R., Mental Retardation: The Known and the Unknown, supra note 25, at 68.

2. Adaptive Egalitarianism and the Integration Imperative

In the past, government leaders created a policy of containment and segregation of mentally retarded people. Laws, institutions and public policies called for the mentally retarded to be "put away" for life. Those archaic and destructive views - and the custodial institutions they fostered - are only slowly being eroded. Indeed, as the First Lady recently acknowledged:

> As a nation, we are still running away from persons who have had or still have mental and emotional disorders. And the stigma attached to their plight is an undeserved disgrace.*** Still, we reject those who are the most vulnerable because they have been branded by the old labels that evoke fear or repulsion.32/

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30. For a review of that literature, see Wortis, "Poverty and Retardation: Social Aspects" and Wortis, "Poverty and Retardation: Biosocial factors", in J. Wortis (Ed), I. Mental Retardation: An Annual Review 262-270 (1970). R. Hurley, Poverty and Mental Retardation: A Causal Relationship (1969).

31. P.C.M.R. - N.A.R.C. Conference on the Future of Legal Services for Mentally Retarded Persons (Sept. 28, 1977).

32. R. Carter, "Removing the Mental-Illness Stigma", The New York Times, Nov. 18, 1977 at A31, col. 1.

To displace stereotype and prejudice, law and science have begun to fashion an egalitarian model of services for retarded persons. Traditional civil disability or charitable approaches have given way to an "adaptive egalitariarism" that focuses on extending and enforcing the rights that mentally disabled persons share with other citizens. An adaptive egalitarian framework meets the handicapped individual's basic needs through a mixture of generic and specialist services. Those services attempt to maximize social integration and conform, as closely as possible, to the general norms of society.33/ A classic example of this is contained in laws making education available to all handicapped children within the overall public education system. This adaptive egalitarianism also finds legal expression in the standards of equal protection and the integration imperative which underlies Section 504 of the Rehabilitation Act of 1973.34/ It is an approach firmly grounded in common sense, the professional literature and international and national declarations of humanitarian principle.

II. PUBLIC POLICY DIRECTIONS

For well over two decades, policy makers have urged strict limits on institutionalization of mentally retarded persons and a shift toward community

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33. For fuller discussion of those services and the underlying egalitarian model, see Herr, "Rights Into Action: Protecting Human Rights of the Mentally Handicapped," 26 Cath. U. L. Rev. 203, 216-228, 304-308 (1977).

34. 29 U.S.C. Sec. 794. See e.g., Halderman v. Pennhurst State School, 446 F. Supp. 1295, 1321-24 (1977).

base care. This consensus is embodied in United Nations Declaratons,[35] World Health Organization reports,[36] professional and scientific literature[37] and national policy statements.[38] In the United States, the principle of the "least restrictive alternative" has been expressed in statute, regulation and judicial decision.[39] While the principle has won broad official and public acceptance, considerable obstacles to its implementation remain.[40] This Section will review international, professional and national policy standards limiting institutional care and requiring community based alternatives.

A. *The International Consensus*

International declarations and reports clearly document a movement away from institutions and a changing outlook on mental retardation care and legislation.[41] As early as 1953, the World Health Organization cautioned

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35. Declaration on the Rights of Mentally Retarded Persons, G.A. Res. 2856, 26 U.N. GAOR, Supp. (No. 29) 93-94, U.N. Doc. A/8429 (1971) (hereinafter cited as 1971 U.N. Declaration); Declaration on the Rights of Disabled Persons, G.A. Res. 3447, 30 U.N. GAOR, Supp. (No. 34) 88, U.N. Doc. A/10034 (1975). Discussed *infra* text at notes 56-66.

36. World Health Organization Technical Report Series No. 75, *The Mentally Subnormal Child*, (1954) (hereinafter WHO Report No. 75); World Health Organization, Technical Report Series No. 392, *Organization of Services for the Mentally Retarded* (1968) (Fifteenth Report of the WHO Expert Committee on Mental Health).

37. M. Bayley, *Mental Handicap and Community Care: A Study of Mentally Handicapped People in Sheffield* (1973); J. Tizard, Sinclair & Clarke, *Varieties of Residential Experiences* (1975). See text and notes at II. B., *infra*.

38. See text and notes at II. C, *infra*.

39. See, e.g., Developmentally Disabled Assistance and Bill of Rights Act, 42 U.S.C. Sec. 6010(2)(1977); Mass. Gen. Laws Ann. Ch. 123. Sec. 8(c) (West 1977).

40. See Comptroller General of the United States, Report to the Congress, *Returning the Mentally Disabled to the Community: Government Needs to Do More* (HRD - 76 - 152) (Jan. 7, 1977).

41. See references at notes 35-36.

against legislative "over-protection" and pointed to the risks of "vested interests" employing protective legislation to guard their own rights rather than those of handicapped persons.42/ WHO Report No. 75 recommended home care for the retarded child as a general rule, explaining that even children with severe handicaps "may be kept at home if the parents are able to take a realistic view of the situation and if they are able to make full use of comprehensive maternal and child health services.43/ Taking strong exception to the "growing practice of very early institutionalization," the Committee concluded:

> No institution can provide an adequate substitute for the essential emotional interaction between parents and child, and this opportunity for interplay is of paramount importance in the case of the handicapped child whose parents can only slowly evolve a realistic and constructive attitude towards this situation . . . . It can be denied categorically that all such infants should be institutionalized at once.44/

The needs of mentally handicapped children, the Joint Expert Committee stressed, should "as far as possible" be covered within the framework of more general legislation protecting the rights and providing for the needs of all children.45/ General legislation, in the Committee's view, rather than relieving education or local health authorities of the responsibility of serving the more handicapped, should impose an obligation to provide "educational and welfare services for all children."46/ The Report urged

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42. WHO Report No. 75, supra note 36, at 39.

43. Id. at 16.

44. Id. at 17. For express agreement with that statement, see WHO 15th Report, supra note 36, at 33.

45. Id. at 39.

46. Id. at 39-40.

countries to explore fully the availability of foster homes and other types of child welfare placements for those handicapped children who might require placements outside their natural home.47/ Legal machinery, too often used to exclude the retarded from services, was seen as needed "to ensure that the authorities carried out obligations which, as regards other children, are accepted as statutory in every developed country."48/ In addition, the Committee recognized the need for some special legislation which, as "a matter of course," would ensure that "adequate supervision of institutions of all kinds caring for the subnormal is available."49/

Fourteen years later, the Fifteenth Report of the WHO Expert Committee on Mental Health50/ criticized in even stronger terms discrimination imposed on the retarded by paternalistic laws. "So-called protective legislation," the report warned, "can easily become discriminatory legislation."51/ It noted with approval new legislation which shifted the emphasis from protection against mentally retarded persons to protection of mentally retarded persons.52/ The WHO Expert Committee urged a "continuum" of facilities and comprehensive services to provide care and support for mentally retarded

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47. Id. at 18.

48. Id. at 40.

49. Id. at 40.

50. WHO Technical Report Series No. 392, supra note 36.

51. Id. at 31.

52. Id. Modern approaches were seen as moving away from the earlier rather primitive and restrictive aims of trying to protect society towards "definitions and actions that are aimed at assisting or protecting the handicapped or allowing them to utilize their capacity for independence." Id. at 10. The Committee observed: "Increasing care is shown about preserving personal rights that would help the mentally retarded person to the greatest possible fulfillment of his life within the limits of his capacity, such as his right to work, to participate in the activities of the community, and to marry. Id. at 31.

children and adults.53/ In lieu of segregated institutions, the Committee again recommended that "whenever possible, the mentally retarded person should be kept with his family and in the community."54/ Families with handicapped members, it recognized, should be provided with the necessary financial and practical support, including adequate day-care facilities for education, training and employment.

The WHO Fifteenth Report clearly adopted an egalitarian position on basic rights and access to services: services and facilities open to other citizens must in principle be available to the mentally retarded. In its discussion of legal considerations, the Committee recorded:

> a consensus that the retarded should enjoy the same rights and privileges of citizenship as their fellow countrymen, unless there are specific reasons for taking legal steps to curtail these rights and privileges.55/

That global consensus is now formally embodied in the Declaration of the Rights of Mentally Retarded Persons adopted by the United Nations General Assembly, without dissent, on December 20, 1971.56/ Member nations thereby pledged to promote the integration of mentally retarded persons "as far as possible in normal life" and to guarantee them "to the maximum degree of feasibility, the same rights as other human beings."57/

Article II further declared the retarded person's right to habilitation and other educational services, specifically "a right to proper medical care

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53. Id. at 32.

54. Id. at 54.

55. Id. at 31.

56. 1971 U.N. Declaration, supra note 35.

57. Id, art. I.

and physical therapy and to such education, training, rehabilitation and guidance as will enable him to develop his ability and maximum potential."58/

The General Assembly resolution reflected the strong presumption in favor of care in family and community settings rather than in an institution. Article IV emphasized that, if residential care became necessary, such care should be provided "in surroundings and other circumstances as close as possible to those of normal life."59/ The Declaration specified the mentally retarded person's rights to "protection from exploitation, abuse and degrading treatment,"60/ to "economic security and to a decent standard of living,"61/ and to "a qualified guardian" if necessary to protect his or her personal well-being and interests.62/ To prevent unwarranted restriction of individual rights, it required "proper legal safeguards against every form of abuse," including expert evaluation of the mentally retarded person's social capability, periodic review and the "right to appeal to higher authorities."63/

Together with the 1975 United Nation's Declaration on the Rights of Disabled Persons,64/this Declaration provides a rough yardstick by which deviations from international norms can be measured. Indeed, the 1971

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58. Id., art. II.

59. That article further states: "Whenever possible, the mentally retarded person should live with his own family or with foster parents and participate in different forms of community life. The family with which he lives should receive assistance."

60. Id., art. VI.

61. Id., art. III.

62. Id., art. V.

63. Id., art. VII.

64. Cited supra note 35.

Declaration has been cited in support of new Federal legislation, judicial action and public information campaigns to strengthen the rights and status of mentally retarded persons.65/ Legal assistance, as Article XI of the 1975 Declaration recognizes, is a vital means to enforcement of those rights: "Disabled persons shall be able to avail themselves of qualified legal aid when such aid proves indispensable for the protection of their persons or property."66/ It is, however, at national, state and local levels that these international principles must be translated into binding legal standards and tangible policy commitments.

B. American Scientific and Professional Views

In endorsing the 1971 United Nations Declaration, American professional associations have adopted official positions supporting the right to adequate care and treatment in least restrictive surroundings. The American Association on Mental Deficiency, the nation's largest organization of mental retardation professionals, reminded its members of their obligation to implement basic rights of retarded persons, including the right "to live in the least restrictive individually appropriate environment" and "to be a part of a family."67/ Moreover, the Association, as plaintiff and *amicus curiae*,

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65. See, e.g., *Wyatt* v. *Stickney*, 344 F. Supp. 387, 390 (M.D. Ala. 1972). See also, Herr, "Rights Into Action," 26 *Cath. U. L. Rev.* 203, 215-16 (1977).

66. Declaration on the Rights of Disabled Persons, *supra* note 35, art. XI.

67. American Ass'n on Mental Deficiency, Rights of Mentally Retarded Persons: An Official Statement, reprinted in *Mental Retardation* 56 (Oct. 1973).

has encouraged the use of "moral, ethical and legal"68/ means to remedy violation of these rights.

By late 1975, the American Psychiatric Association joined in supporting a similar position.69/ The A.P.A. recognized that a history of discrimination against the mentally disabled had resulted in inadequate care and treatment, "especially in public hospitals which are usually underfunded and consequently understaffed."70/ It therefore endorsed a legal right to care and treatment, noting that "indices of adequate care" could be objectively formulated "with reasonable ease and precision," while adequate treatment criteria posed a technically feasible but more controversial task.

The Association's position glossed over some troubling issues. Acknowledging the "crucial difference" between the recognition of a right and its effective enforcement, the APA maintained that an increase in "actual facilities and staff resources" would secure "actual implementation of the effective right to adequate care and treatment." Implementing that right would require the "availability of treatment staff adequate in both competence and concern working in a proper environment."71/ The issues avoided were whether large, remote institutions could, or should be proper environments for providing treatment or recruiting competent staff.

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68. Id. See, e.g., Wyatt v. Stickney, 344 F. Supp. 387 (M.D. Ala. 1972); Morales v. Turman, 364 F. Supp. 166 (E.D. Tex. 1973); Souder v. Brennan, 367 F. Supp. 808 (D. D.C. 1973); Townsend v. Treadway, Civil No. 6500 (M.D. Tenn. 1973).

69. 134 Am. J. Psychiatry 354 (March 1977).

70. Id. In the Wyatt appeal, the American Psychiatric Association joined the ACLU and other associations in a joint amici brief. Wyatt v. Aderholt, 503 F.2d. 1305, 1308 (5th Cir. 1974).

71. Id.

C. The Rise of the Developmental Model

Recent legislation has repudiated the traditional institutional model of care for mentally retarded persons. That model, built upon pessimistic assumptions about mental retardation, viewed retarded persons as "hopeless," "incurable" and "mistakes of nature." Society's discomfort with and prejudice against those with mental and physical handicaps generated other self-serving myths and stereotypes. Mentally retarded persons, it was falsely assumed, would be better off "put away" for life in segregated facilities.

Given these stereotypes, lawmakers and caretakers of the past had little incentive to fund or operate adequate training programs for people seen as going nowhere. "As long as our most vulnerable citizens suffer from a stereotyped image," the First Lady, Rosalyn Carter, observed, "they will suffer from discriminatory zoning laws, rejection in the work market, and inappropriate facilities. . ."72/ The American Psychiatric Association put the problem more baldly: people institutionalized as mentally disordered, "rendered invisible by removal to large and remote state institutions," may be provided "mere custody in an environment that does not allow a minimum level of humane care."73/ Unfortunately, many retardation institutions failed to provide even custodial safekeeping, subjecting their residents to debilitating conditions.74/

The developmental model of mental retardation rejected custodial care, viewing retardation as a dynamic rather than a static condition. Mentally retarded persons, like all others, undergo behavioral changes, with the

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72. Carter, "Removing the Mental Illness Stigma," The New York Times, Nov. 18, 1977 at A31, col. 1.

73. 134 Am. J. Psychiatry 354 (March 1977).

74. See Wyatt v. Aderholt, 503 F.2d 1305, 1313 (5th Cir. 1974).

direction and rate of these changes influenced by learning and living environments. Training programs for mentally retarded persons -- broadly termed "habilitation" -- seek to modify the rate and direction of change so as to improve the individual's skills or levels of adjustment.75/

No line divides those mentally retarded persons who can benefit from habilitation from those who cannot; on the contrary, even the most profoundly retarded "can and do profit from habilitation efforts."76/ As the United States District Court found, the evidence "is overwhelming and convincing that a program of habilitation can work . . . that everyone, no matter the degree or severity of retardation, is capable of growth and development if given adequate and suitable treatment."77/ Although habilitation is a broad concept, experts have formulated standards by which to judge the adequacy and suitability of habilitation efforts. Confining mentally retarded persons in large, understaffed and overcrowded total institutions deviates so dramatically from these standards as to require the most exacting scrutiny. The open question is whether these matters should be left to case by case adjudication or whether policy decisions should accelerate the transition from institutional to community care alternatives.

As early as 1972, that question was posed before a United States District Court in the class action for the 2300 residents of Alabama's Partlow State School and Hospital.78/ Professor Gunnar Dybwad, consultant to the World Health Organization and to the President's Committee on Mental

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75. Roos, "Mentally Retarded Citizens: Challenge for the 1970's," 23 Syracuse L. Rev. 1059, 1065-66 (1972).

76. Welsch v. Likens, No. 4-72 & Civ. 451 (D. Minn. Oct. 1, 1974). (Unpublished findings of fact and conclusions of law).

77. Welsch v. Likens, 373 F. Supp. 487, 495 (D. Minn. 1974).

78. Wyatt v. Stickney, 344 F. Supp. 387 (M.D. Ala. 1972).

Retardation, was asked if there was a need or a role for that institution in future mental retardation programming. In response he testified, "In the long run, I see no need for Partlow. In the immediate future -- that is, over whatever time will be considered feasible -- I would not make a specific judgment. Partlow's function is to be dephased, to be dephased out of existence. Obviously this will take planning; but if Partlow will exist over the next years, it will be to take itself out of business."79/

Dr. Dybwad made clear that this conclusion was not limited to any single institution, but was premised on facts with far-reaching implications. His testimony, consistent with the international and professional consensus in favor of community based care and "deinstitutionalization," concluded that:

> the era of the justifiable existence for institutions such as Partlow, and to state schools in general throughout the country, has passed. We have new knowledge about human behavior, about the ways in which human beings learn, and can teach methods of intervention which make these institutions no longer necessary. We know that a very substantial percentage of the individuals now in our state institutions can immediately be placed in the community -- by immediately, I mean exactly that -- provided there is a place to move them, in the open community. I would assert very definitely that there is a second very considerable percentage of individuals who, with a relatively quick and intensive training program, habilitation program. . . would be prepared to live in the community, under a variety of circumstances -- small houses, with more or less supervison. I want to emphasize that as far as a good number of my colleagues are concerned, both in this country and abroad, the remaining group, those who require specialized services, need not, for any rational reason be kept in an institution of this nature. They can be accommodated where other people can be accommodated in the community such as with extensions to community hospitals and so on.80/

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79. Record at 26.

80. Record at 24-25.

Critiques of mental retardation institutions rest on evidence of tangible harm to residents, not on mere ideology. The urgent demand for community alternatives derives, in part, from empirical studies on the superiority of home-like settings and the risks of institutionalization. Official investigations have revealed abuses of residents, "abuses of omission as well as abuses of commision"81/ in both public and private institutions.82/ Newspapers around the country have reported shockingly widespread maltreatment of the residents of state mental retardation facilities.83/ Accreditation surveys document a pattern of disregard for residents' rights: excessive use of physical seclusion and chemical restraints; residents admitted and retained

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81. Governor's Task Force on Abuse in Mental Retardation Facilities, Report of Interm Findings (June 15, 1977, Illinois Association for Retarded Citizens) (covering letter from Don Moss to Governor Thompson at 4). "Tranquilizers Held as an Agent in Deaths of Mental Patients," The New York Times, at A1, col. 1 (July 17, 1978). (Rockland County Medical Examiner found "a large percentage of deaths" from Letchworth Development Center and Rockland Psychiatric Center "are tranquilizer-related").

82. Report of the Mental Health Information Services on the Adequacy of the Current Grievance and Disciplinary Procedures of the Department of Mental Hygiene in Safeguarding the Rights of Patients Involved in Incidents of Abuse and Mistreatment (submitted to the Legislature of the State of New York pursuant to the direction of chapter 334 of the Laws of New York, 1976) at 7.

83. "Judge Tauro Tours 'nightmare' - Wrentham State School, "Boston Globe, April 28, 1977, at 1, col. 1; "Retarded Abused," Chicago Sunday Sun-Times, May 15, 1977, at 1, col. 1; Editorial: "Mr. Yeldell and Forest Haven, "The Washington Post, May 10, 1976, at 18, col.1; "Closing of Facility for Retarded Suggested," Rocky Mountain News, May 21, 1977, at 6, col. 1. See also Editorial: "States Rights vs. Victims Rights," The New York Times, May 8, 1977, at 19, col. 2:

> However poor a state's purse and however precious its autonomy, it must still subscribe to the Constitution of the United States. And to our reading that document says with majestic clarity that there are some powers — like practicing or condoning brutality - that a state may not retain; there are some economies — like depriving the feebleminded of care — that a state may not demand.

without proper evaluation or periodic review; and the denial of "due process and other legal rights of the residents and their families."84/

Institutionalization in barren, non-stimulating environments leads to deterioration in residents' behavior.85/ Testimony shows that residents who once spoke, stop speaking; that residents who once walked, stop walking. In short, people lose their skills for self-help and autonomy. The impersonal care of the institution produces detached, often bizarre, sometimes self-destructive behavior.86/ Residents' tested intelligence declines.87/ As one review of the scientific literature concluded, "most institutional environments which have been studied do have adverse effects on the development of retarded children."88/

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84. D. Braddock, Opening Closed Doors: The Deinstitutionalization of Disabled Persons 99 (Council for Exceptional Children, 1977). These findings were provided by the Accreditation Council for Facilities for the Mentally Retarded, based on site surveys of 48 residential facilities in 21 states through September 1974. Id. at 52-74.

85. R. King, N. Raynes & J. Tizard, Patterns of Residential Care: Sociological Studies in Institutions for Handicapped Children, (1971), (group homes of 12-41 residents found more resident-oriented, while state institutions of 121-1650 residents were more institution-oriented in care practices). Zigler & Balla, "Impact of Institutional Experience on the Behavior and Development of Retarded Persons," 82 Amer. J. of Mental Deficiency 2 (1977): "Retarded individuals have a right to humane care and treatment whether or not such care ultimately results in greater behavioral growth."

86. On the emotional deprivations resulting from placement in institutional settings, see Spitz, "Hospitalism: An Inquiry Into the Genesis of Psychiatric Conditions in Early Childhood," 1. Pschoanalytical Study of the Child 53 (1945), J. Bowlby, Maternal Care and Mental Health (1951).

87. See e.g., Sternlicht & Siegel, "Institutional Residence and Intellectual Functioning," 12 J. Mental Def. Research 119 (1968) (average decrease of 10 I.Q. points over 4 year period for institutionalized children, and trend towards depression for adolescents and adults).

88. D. Pilling, The Handicapped Child: Research Review 80 (1973).

D. Federal Policy Directions

National policy has not yet fully responded to the burden of this knowledge. For the future, planners project an increase in the population at high risk of custody in large, long-term institutions. Despite several decades of demands for redirection of resources to out-patient care, fifty-six cents of each mental health dollar spent in the United States goes to inpatient and long-term institutional services. Since 1970, the share of total Federal assistance for community health care and social services has actually declined from 37 to 31 percent, while the share for long-term and inpatient care has risen from 63 to 69 percent.89/ As the following discussion shows, this trend runs directly counter to the policy goals of five successive Presidental administrations.

The Federal government is the "sleeping giant" in the residential services field. For over 16 years, successive administrations have called for deinstitutionalization and enhanced protection of residents' rights.90/ In recent years, state and local service delivery programs have grown increasingly dependent on Federal subsidies. Where larger, long-term care facilities were once totally state and local government supported, today the Federal government bears 57 percent of their Medicaid-reimbursable cost.91/

The Federal role in institutional care has steadily expanded since the 1960's. Through various systems of Federal financial assistance to state and local mental retardation programs, the government has now emerged as a prime

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89. U.S. Dept. of Health, Education and Welfare, Office of the Secretary, Budget Analysis of Federal Spending for Services to the Mentally Disabled (Annex 10, unpublished report, June 1978) at 1.

90. See discussion in text and notes at notes 96-131, *infra*.

91. Annex 10, at 2.

funding agent and standard setter. Under the Medicaid and Medicare programs, for example, more than $3.6 billion annually is spent for long-term and mental hospital care of mentally retarded and mentally ill persons.92/ State administration of institutional programs for the retarded is now particularly influenced by the amount and types of Federal financial assistance and the standards, requirements and policies that assistance imposes. The Federal government now supplies in excess of 900 million dollars per year for the upkeep of state mental retardation institutions.93/ Most of those Federal funds are derived from Medicaid Title XIX reimbursements, with other funds drawn from education, vocational rehabilitation and developmental disabilities programs. While some states have used Medicaid funds for group home facilities for the mentally retarded, most of them have simply relied on Title XIX for a major share of institutional budgets.

This funding pattern runs counter to the long line of policy statements committing the Federal government to "deinstitutionalization" and the establishment of community mental retardation centers. While pointing state mental retardation programmers toward the community, the United States Government liberally funds institutional programs.94/ Funding, inertia and political pressure all contribute to the nullification of community-based

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92. HEW, Annex 10, supra note 89, at 7.

93. Telephone interview with Robert Getting, Executive Director, National Association of Coordinators of State Programs for the Mentally Retarded, (Jan. 23, 1979). There is little hard data on the extent to which Federal dollars go into institutions of this kind. One point is clear: the Federal funding contribution has risen rapidly, from $110 million in 1968 and $196 million in 1970. R. Conley, The Economics of Mental Retardation, (1973).

94. While community social services under Title XX have been held to a ceiling of $2.5 billion, the institutional care component of the Medicaid budget has gone unchecked. At present, economic rationality encourages the states to capture the increased Federal funding for institutional "solutions" for caring for mentally disabled persons, rather than community ones.

service policies.95/ While basic critiques of institutions multiplied, financial support for institutions has actually increased.

Before the infusion of Federal resources, regulation of retardation residential services was exclusively a state function.96/ President Kennedy's interest in mental retardation led to the creation of a Federal role and gave the problems of retardation care greater visibility. The President's Panel on Mental Retardation, appointed in 1961, urged that programs for retarded people be community-centered and organized so as to provide a full continuum of services.97/ A Task Force on Law chaired by Chief Judge David L. Bazelon forcefully pointed out that, in dealing with mental retardation, the law "must combat many years of general ignorance, prejudice and superstition."98/ In providing care, it recommended minimizing coercive intervention, viewing the courts as "a residual resource" when other social agencies failed to protect the retarded person's rights.99/ The Panel's basic position was that "all rights normally held by anyone are also held by the retarded."100/ Any

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95. The states also subverted those policies through massive "dumping" of ex-residents and ex-patients. As The New York Times recently put it in a generalization that could apply to most parts of the country, "New York State must take much of the blame for the halfway revolution" which discharged mental patients without adequate aftercare and support.

96. Prior to the 1960's, the Federal role in this field was minimal, derivative of initiatives directed to relieve mental illness. Often mental retardation was entirely overlooked, or was an afterthought in formulating mental disability policy. Federally financed studies concerning that law and policy often omitted topics bearing on mentally retarded persons.

97. President's Panel on Mental Retardation, National Action to Combat Mental Retardation (GPO 1962).

98. President's Panel on Mental Retardation, Report of the Task Force on Law (GPO 1963).

99. Id. at 17-18.

100. Id. at 20.

limitations on those rights were to be narrowly circumscribed by "a network of authorized checks and balances," and safeguarded by the retarded person's easy resort to a partisan spokesman and to the courts.101/ Stressing that protection of personal and civil rights did not end with an admission decision, the Panel urged that independent, external review be available throughout a resident's institutional career. Accordingly, the Task Force warned that:

> Protection of these rights cannot, in our opinion, be completely delegated by the courts to non-judicial personnel. Where there is partial delegation, as when a retardate is placed in the custody of a superintendent of a residential center or under the care of a guardian, an appeal by or on behalf of the retardate must always be available from their decisions.102/

The Panel recognized the resident's absolute right to communicate with lawyers and legal authorities in order to challenge the validity of continued confinement or the nature of care and treatment. They were equally clear that "(p)rocedures must be readily available by which all such challenges, not plainly frivolous, receive prompt attention."103/ This sound recommendation was undermined by the Panel's inattention to the lack of appeal procedures in most institutions. Given that context, the Panel Report introduced a jarring note of unreality by assuming that a resident would be able to exercise the "right . . . to get in touch with legal authorities, with his lawyers, his

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101. Id. at 19: "It is a basic democratic principle that no diminution of human rights and human dignity can be countenanced by law for any person -- let alone any class of persons -- except for good reason, following due process, and then to the minimum degree necessary and for the shortest period possible.

102. Id. at 20.

103. Id. at 30.

guardians or others. . . ."104/ How would residents lacking contacts, sophistication or communication skills get in touch with anyone? Which legal authorities were under any duty to respond to a resident's petition? To whom would a resident without an involved guardian or friend-advocate turn for help? If access to counsel were limited to those already within a lawyer-client relationship, the vast majority of residents would remain without legal assistance.

The Kennedy Administration's mental retardation legislation failed to address these issues of individual rights. Instead, Federal laws, such as the Maternal and Child Health and Mental Retardation Planning Amendments,105/ simply provided funds to encourage planning, service provision and facility construction. Title I, the Mental Retardation Facilities Construction Act, for example, authorized grants to states and public or non-profit private agencies for community mental retardation facilities. Community programs, never adequately defined, came to refer to a program "serving the needs of the particular community or communities in or near which the facility is situated."106/ Over the next decade, only $90,000,000 in Federal funds were actually spent for these purposes.107/ Moreover, only a fraction of that expenditure was for small residential facilities located in ordinary residential neighborhoods.

Congress has repeatedly expressed its preference for community mental health centers over institutional care, finding such centers to be "the most

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104. Id.

105. 42 U.S.C. Secs. 1391-1394 (1974).

106. 42 U.S.C. Sec. 2678(a) (1973).

107. D. Braddock, Opening Closed Doors 11 (1977) For deficiencies in the administration of community mental health centers, see F. Chu & S. Trotter, The Madness Establishment (1974).

effective and humane form of care for a majority of mentally ill individuals."108/ In the mental retardation field, similar findings and needs have long been accepted,109/ but regulatory directions have not been specific. In 1970, the Secretary of HEW was to promulgate regulations "as soon as practicable" concerning the needed retardation services, the "scope and quality" of those services and the standards for facilities.110/ Nearly two years elapsed before that Department adopted regulations of the most general character.111/

Presidential statements, time after time, have articulated a national goal of deinstitutionalization without redirecting the national resources to attain it. The Kennedy Administration made a hopeful beginning, but its "blueprint" for "national action to combat mental retardation" had little impact on those in institutions.112/ President Johnson's "War on Poverty" yielded indirect benefits for retarded or allegedly retarded persons. The President's Committee on Mental Retardation (PCMR), which he established to evaluate "the adequacy of the national effort to combat mental retardation,"

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108. P.L. 94-63, Sec. 302(a)(1), noted at 42 U.S.C. Sec. 2689 (1978 Supp.).

109. See, e.g., 42 U.S.C. Sec. 2677b (1973).

110. 42 U.S.C. Sec. 2677b(b),(d). 37 Fed. Reg. 18425, (1972).

111. 45 C.F.R. Part 416.

112. U.S. President's Panel on Mental Retardation, A Proposed Program for National Action to Combat Mental Retardation (GPO 1962). The Panel urged automatic judicial review at two year intervals of persons admitted to institutions, and a protective service agency to supervise guardians monitoring a resident's treatment. *Id.* at 153. It failed, however, to implement these measures or to recognize that initial admission decisions required special legal regulation.

primarily told the country how badly the battle was going.113/ While the President's statements were forcefully egalitarian, his combat troops were missing.

The pace of change since the 1960's, in the words of the PCMR, has proven "gallingly slow."114/ It took the PCMR four years to issue "an action policy proposal" intended to undo the neglect of the institutionalized retarded.115/ That policy remained more a proposal than an action plan. It recognized that residential facilities should be used for programming not punishment and that "the mentally retarded shall have the same constitutional rights and guarantees as every other American citizen."116/ However, it stopped short of developing these principles into a plan to replace segregated, inferior state institutions with alternative service delivery systems. In the end, the Committee simply decried, "the institutionalized dehumanization and neglect to which we have so long relegated many of our mentally retarded under the guise of care and concern."117/

In 1971, President Nixon proclaimed a national commitment to community placement for mentally retarded persons as "a realistic goal," and pledged "continuing expansion" of Federal spending to "open better lives for the

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113. The PCMR, like the three Presidents who have extended its term, produced helpful statements of mental retardation policy, but not the substance of policy. As an advisory body, the PCMR had no power to carry out its recommendations. It viewed itself as the broker of "meaningful dialogue" between those who "clamor for immediate reform" and the superintendents and program directors who "restricted by budget and personnel problems" felt stymied in making desired changes. P.C.M.R., MR 70: The Decisive Decade 1 (1971).

114. Id. at 2.

115. P.C.M.R., Residential Services for the Mentally Retarded: An Action Policy Proposal, (GPO 1970).

116. Id. at 3.

117. P.C.M.R., supra note 113, at 1.

mentally retarded."118/ This statement set out two major national goals: reduce by half the occurrence of mental retardation, and enable "one third of the more than 200,000 retarded persons in public institutions to return to useful lives in the community." The latter goal was seen as achievable, indeed, "possible in the immediate present." To do so would require improved review procedures within institutions "aimed at identifying persons ready to enter the community" as well as counseling, job training and placement services, special education classes and suitable living arrangements for persons resettling in the community. President Ford similarly spoke of the urgency of charting a "concerted effort" to realize those aims and "full citizenship" for those who are retarded.119/ Consigning that effort to a presidential advisory committee without the executive authority to move Federal agencies produced little substantive change.

In January 1977, in a report to the Congress, the Comptroller General identified numerous weaknesses in Federal policy aimed at the deinstitutionalization of the mentally disabled.120/ Though deinstitutionalization has been described as a national goal since 1963,121/ the GAO report concluded that relevant Federal agencies had not yet developed "a comprehensive and clearly defined national plan to achieve the goal," and, for the most part, had made

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118. "Statement of President Nixon following his meeting with the President's Committee on Mental Retardation," November 16, 1971, 7 Weekly Compilation of Presidential Documents 1530 (1971).

119. Statement of President Ford, Oct. 11, 1974, Weekly Compilation of Presidential Documents 1270, 1271 (1974). He noted the "great progress... in winning legal recognition for the rights of retarded persons... (including) the right not to be confined in an institution without habilitative treatment." Id.

120. Comptroller General of the United States, Returning the Mentally Disabled to the Community: Government Needs to Do More (Jan. 7, 1977).

121. Id. at i, 1.

"no concerted efforts" to accomplish the deinstitutionalization goal.122/ With respect to the developmentally disabled, the Comptroller General found that, if the Developmentally Disabled Assistance and Bill of Rights Act were effectively implemented, many of those problems could be resolved. He noted, however, that "without greater commitment and cooperation of other federally supported programs at the state and local level, it will be difficult to achieve the Act's objectives."123/

The GAO findings showed that existing Federal programs had "a positive, but limited impact on deinstitutionalization."124/ Developmental disability programs, in particular, had only limited funds, authority or influence to bring about corrective state policies. Although state Developmental Disabilities Councils identified wide gaps in community-based services and facilities, the bulk of state mental retardation budgets has continued to support care in institutions.125/ Despite a decline of 7.5% in the resident populations of public retardation institutions between 1971-1975,126/states have not reallocated those budgets to reflect increasing needs for aftercare and community care. The basic dilemma is to press for that reallocation in a way which protects the interests of both currently institutionalized retarded persons and those who now live in the community.

On February 17, 1977, President Carter created the President's Commission on Mental Health as a temporary study commission. Its basic charge

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122. Id. at 26.

123. Id. Summary of Report at 10.

124. Id. at 53.

125. Id. at 56, citing, as an example, the Maryland Mental Retardation Administration, with 80% of its 1975 budget reserved for institutional programs.

126. Summary, at 3.

was to report "how the mental health needs of the Nation can be met and identify the relative priority of those needs,"127/ including the various ways the President, the Congress and the Federal government might most efficiently support the treatment of the underserved mentally ill, emotionally disturbed and mentally retarded.128/

The formation of yet another Presidential Commission and the call for a new round of reports and studies raises the spectre of replication of past efforts.129/ Yet, it also symbolizes high-level administration concern for the mentally disabled and some awareness of how deep and long-standing is their national neglect. As described by President Carter, the Commission is concerned for "those who have been bereft of care for years and who are at the mercy of governmental agencies and sometimes neighbors and friends who haven't seen their affliction. . ."130/ The prospect of another grand Federal policy reassessment should not obscure the need for more intensive legal advocacy efforts. Indeed, the Commission has called for the establishment of advocacy systems for the representation of mentally disabled individuals and emphasized the need for the appointment of counsel in civil commitment and guardianship cases and for the implementation of rights to receive treatment in the least restrictive setting and to refuse treatment.131/ Nor should the Commission's

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127. Executive Order 11973, Sec. 2(b) (February 17, 1977) in 13 Weekly Compilation of Presidential Documents 220 (1977).

128. Id. at Sec. 2(a)(3).

129. Remarks of the President and Mrs. Carter at the Signing Ceremony of Executive Order 11973 establishing the President's Commission on Mental Health, Feb. 17, 1977, 13 Weekly Compilation of Presidential Documents 218 (1977).

130. Id. at 219.

131. The President's Commission on Mental Health, Report to the President 42-44, 70-71 (1978).

report distract attention from the states' prime responsibilities in caring for retarded persons within their communities, near families, friends and homes.

E. State Legislative Purposes: The New York Case Study

New York is a classic example of the pitfalls of changing mental disability laws without changing underlying practices. In terms of liberal promises, the legislative policy contained in the New York Mental Hygiene Law of 1972 seemed to represent an advance. With the prevention of mental retardation and the protection and promotion of mental health recognized as matters of public concern, state and local governments were assigned the tasks of implementing that policy and sharing responsibility for developing plans, programs and services for the care, treatment and rehabilitation of the mentally retarded, the mentally ill and the developmentally disabled whose conditions, including but not limited to cerebral palsy and epilepsy, are associated with mental disabilities.132/

In providing those services and programs, the Legislature directed that full use be made of community resources. Acknowledging the value of a multidisciplinary model, the law recognized the "important therapeutic role" of all disciplines involved with the care and treatment of the mentally disabled.133/ To pinpoint authority, the Department of Mental Hygiene and its Commissioner were charged with the responsibility for planning and providing the contem-

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132. New York Mental Hygiene Law, Sec. 1.03. For a critique of laws defining those joint responsibilities, see Note: "The Local and Unified Services Act," 23 Buffalo L. Rev. 785 (1973).

133. This interdisciplinary orientation weakened the medical model and prevented any medical monopoly in developing programs.

plated comprehensive services.134/ Moreover, the Department has the clear statutory obligation under Section 7.05 (c) to safeguard the rights and interests of its mentally disabled clients:

> The Department shall have the responsibility for seeing that the classes of persons specified are provided with care and treatment, that such care and treatment is of high quality and effectiveness, and that the personal and civil rights of persons receiving care and treatment are adequately protected.135/

Facilities for the mentally disabled were unmistakably intended to be rehabilitative, not punitive.136/ By statute, state hospitals were designated "for the care and treatment of the mentally disabled,"137/while state schools were "for the care, treatment, training and education of the mentally retarded."138/ Those were, however, schools in name only; formerly known as state institutions for mental defectives, and renamed "developmental centers," they remain measures of last resort. The Commissioner, charged by law to "take all actions" necessary to provide a continuum of service,139/was to "plan, promote, establish, coordinate, evaluate and conduct" a full range of programs for the mentally retarded. The legislation specified that such programs:

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134. New York Mental Hygiene Law, Section 7.05(a) provides, inter alia, that the Department: "shall have the responsibility for developing comprehensive plans, programs, and services in the areas of research, prevention, and care, treatment, rehabilitation, education, and training of the mentally ill, the mentally retarded, and those suffering from alcoholism, narcotics addiction, or drug abuse."

135. Id. Sec. 7.05(c).

136. Kesselbrenner v. Anonymous, 350 N.Y.S. 2nd 889 (Ct. of App. 1973).

137. New York Mental Hygiene Law, Sec. 7.15(a).

138. Id. Sec. 7.15(b).

139. Id. Sec. 9.03(a).

> shall include but not be limited to inpatient, outpatient, partial hospitalization, day care, emergency, rehabilitative, and other appropriate treatments and services.140/

Had that mandate been fulfilled, the Willowbrook case141/and others like it might not have been brought. The State, however, chose to meet demands for residential care by largely relying on inappropriate institutional placements.142/ Without dispositional alternatives, the institutions clogged up and became cruel caricatures of their care, treatment and educational missions. As waiting lists lengthened or "freezes" on admissions were imposed, eligibility criteria for entry into public institutions became an academic matter.143/ In form, eligibility turned on satisfying statutory definitions of mental retardation and demonstrating a broadly defined need for care and treatment. In reality, rather than strict clinical criteria, the admissions decision often turned on a family's political sophistication, financial resources or the ability of Medicaid providers to justify residential care.

Given this systematic breakdown, departmental mechanisms for protecting

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140. Id.

141. New York State Ass'n for Retarded Children and Parisi v. Rockefeller, 357 F. Supp. 752 (E.D. N.Y. 1973), discussed at Sec. III infra.

142. The state long ago acknowledged that over one third of the entire state school population is suitable for placement in the community. New York Dept. of Mental Hygiene, Appropriateness of the Continued Institutionalization of the State School Population in New York State (1969).

143. New York Assembly Joint Committee to Study the Department of Mental Hygiene, Mental Health in New York (March 1, 1976). By 1975, the number of first admissions to state mental retardation facilities had declined to 539, down from 1560 a decade before. In contrast, for every mental retardation admission some 24 persons were admitted to state mental health facilities.

residents' civil rights remained ill-defined, poorly conceived and woefully underfunded.144/ It was not until three years after the recodification of Mental Hygiene Law that the Department issued regulations concerning the quality of care and treatment.145/ Even then, central issues relating to enforcement of the residents' personal and civil rights were given only cursory attention. For example, problems such as abandonment, lack of guardians or advocates for long-stay residents and abuse of residents were not addressed. Until outside pressure exposed institutional abuses, the Department showed little initiative in setting up programs to monitor and remedy infractions of residents' rights. In New York State, as in other parts of the country, the residents of mental retardation facilities remained vulnerable and unrepresented.

Custodial mental retardation care, almost all admit, wreaks a devastating toll. What, then, sustains the fortress institution? With limited reallocation to community-based care, Federal and state governments continue to pour vast sums of money into large state mental institutions. In New York, for example, 95 percent of "State Retardation purposes" expenditures goes to inpatient mental retardation services. The Florida legislature has had the candor to concede that institutions "are unreasonably costly, are ineffective in bringing the individual client to his or her maximum potential, and are in fact debilitating to a great majority of clients."146/ Similar findings would apply to every state which operates or funds institutions for the retarded. Why, then, do not all states commit themselves to "a

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144. Id. at 204-212. For example, only four inspectors are assigned to check the hundreds of mental disability facilities publicy operated or licensed by the Department. New York Times, March 12, 1976.

145. 14 N.Y. Code of Rules & Regs. Part 27 (1976).

146. Fla. State Ann. Sec. 393.062 (West Supp. 1978).

redirection in state treatment programs" in order to give "greatest priority . . . to the development and implementation of community-based residential placements, services and treatment programs . . . ?"147/ In understanding the survival of notorious custodial institutions, it is too easy to overstate the corrupt motive and political influence. Inertia, convenience, funding patterns, organizational timidity and job preservation all combine to shield institutions from more searching scrutiny.

III. LEGAL ASSISTANCE TO INSTITUTIONAL RESIDENTS

Only in recent years have lawyers begun to discover the 176,000 people residing in public mental retardation institutions.148/ Through class actions,149/individual representation,150/legislative advocacy151/and other strategies,152/a movement of consumers and their lawyers has sought to provide those residents with a sword and a shield. If affirmative action to assure adequate habilitation in community-based settings is the sword, 153/ then protective action to halt institutional abuse, neglect and maltreatment

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147. Id.

148. See text and notes 194-209, infra and M. Kindred, J. Cohen, D. Penrod, & T. Shaffer (Eds), The Mentally Retarded Citizen and the Law (1976) (hereinafter Mentally Retarded Citizen).

149. See discussion at Sections D & E, infra.

150. See discussion at Section F, infra.

151. See discussion at Section G, infra.

152. See discussion on group representation at Section H, infra.

153. See e.g., New York State Association for Retarded Children v. Rockefeller, 357 F. Supp. 752 (E.D.N.Y. 1973), final consent judgment entered, 393 F. Supp. 715 (1975), full text of decree reprinted at I Mental Disability Law Reporter 58-68 (1976); Halderman v. Pennhurst State School & Hospital, (E.D. Pa. 1977). 446 F. Supp. 1295 (E.D. Pa. 1977).

constitutes the shield.154/ The need for such action, however, is not confined to any single type of facility. Other mentally retarded persons facing the risk of custodial or dehumanizing care may be found among the 50,000 persons in private residential facilities, the 29,000 persons in state mental hospitals and the estimated 20,000 inmates in penal institutions.155/ For the most part, these quarter million people have no meaningful access to legal assistance.156/ Beyond institutions, there are between 6 and 10 million developmentally disabled persons157/in the community who constitute one of the most underserved legal aid eligible populations. Without adequate community-based services, many of these persons are in danger of institutionalization.

The most conspicuous abuses of human rights have occurred in the euphemistically titled "state schools and hospitals." Through cases focusing on these segregated, massive institutions for the retarded, Congress, state legislatures and the public have learned of residents who, deprived of

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154. See, e.g., Michigan Association for Retarded Citizens v. Smith, C.A. No. 870384, (E.D. Mich. March 3, 1978) (Consent order on preliminary injunction and class certification); Wheeler v. Glass, 473 F. 2d. 983 (7th Cir. 1973) (restraints on mentally retarded residents found cruel and unusual punishment).

155. Letter from Meryl Weinberg, National Association of Coordinators of State Programs for the Mentally Retarded, to author, Sept. 19, 1977.

156. See American Bar Association, Report to the House of Delegates, Comm'n. on the Mentally Disabled at 1 (1978), and Resolutions approved as policy of the ABA by the Association's House of Delegates, in Summary of Action of the House of Delegates, ABA 1978 Annual Meeting 19-20 (Aug. 1978).

157. Developmentally Disabled Assistance and Bill of Rights Act: Hearings on S. 3378 Before the Subcomm. on the Handicapped of the Senate Comm. on Labor and Public Welfare, 93rd Cong., 2nd Sess. 281 (1974) (statement of Francis Lynch). Mr. Lynch, director of the HEW's Developmental Disability Office, testified that, of the 6-10 million retarded, cerebral palsied, epileptic or other individuals requiring similar services, only about 300,000 received the services of the developmental disabilities program.

training and therapeutic care, lost the skills of talking, walking and self-help. Unlike journalistic exposes or blue-ribbon commissions, these judicial inquiries were too pointed and costly for state and Federal governments to ignore.158/ No longer could the governors and peoples of New York, Alabama or Minnesota claim no knowledge of what happens to residents at Willowbrook159/or Partlow160/or Cambridge State School.161/ Congress, too, has been forced to acknowledge sub-standard conditions which were not regional aberrations but endemic to restrictive, closed institutional care for the retarded.162/ Indeed, the testimony of the Justice Department has gone even

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158. United States District Judge Joseph L. Tauro, who presided over five suits regarding Massachusetts institutions for the retarded, explained that:

> "...These cases have more or less served as a catalyst for social progress. Government, almost by necessity, is a crisis operation. The people in the positions of governor, attorney general, speaker of the House, have so many problems to deal with that they really have to deal with the fire that's hottest at the moment. What happened here is that these cases caused the public officials to pay attention to a problem which - though everyone knew existed - was the type of problem that everyone said, 'We'll have to get to it someday.' Well, I think these cases provided the 'someday,' and I think the publicity given them, through the attention of the news media, generated a great deal of public interest. The combination of these circumstances, I think, led to great progress." The Boston Sunday Globe, July 31, 1977, at 2, col. 3.

159. New York State Ass'n for Retarded Children v. Carey 393 F. Supp. 715 (E.D.N.Y. 1975); New York State Ass'n for Retarded Children v. Rockefeller, 357 F. Supp. 752 (E.D.N.Y. 1973).

160. Wyatt v. Stickney, 344 F. Supp. 373 (M.D. Ala.), 344 F. Supp. 387 (M.D. Ala. 1972), aff'd sub nom., Wyatt v. Aderholt, 503 F. 2d 1305 (5th Cir. 1974).

161. Welsch v. Likins, 373 F. Supp. 487 (D. Minn. 1974), aff'd in part and remanded in part, 550 F. 2d 1122 (8th Cir. 1977), consent decree entered, sub nom. Welsch v. Dirkswager, C.A. No. 4-72 Civil 451 (Dec. 1977).

162. See S. Rep. No. 94-160, 94th Cong., 1st Sess. 37 (1975); Cong. Rec. S. 9362 (daily ed. June 3, 1975) (remarks of Sen. Williams).

further,[163] its representatives pointing out that "the basic constitutional and Federal statutory rights of institutionalized persons are being violated on such a systematic and widespread basis to warrant the attention of the Federal Government."[164]

Isolated test cases of the past could not alter patterns of indifference and lawlessness in the operation of mental retardation institutions. This section describes current efforts to provide legal assistance for mentally retarded persons in general, and for the institutionalized specifically. A central dilemma involves the search for remedies which offer promise of habilitating retarded individuals without rehabilitating deforming institutions. This study reviews several approaches to this end, including structural (omnibus) class actions, discrete class actions, individual representation, legislative and administrative advocacy and group representation. Past efforts demonstrate an inability to mesh these techniques and to follow up class-wide legal gains with individualized legal assistance. Indeed, there is a considerable degree of separation between class action and individual service practitioners, a separation which may frustrate real implementation of the rights of mentally handicapped persons. On the whole, too little work now goes on at the grass-roots level to notify and educate mentally retarded persons, their relations, guardians and friends, of a rapidly expanding array of rights. As a result of this dearth of legal counseling, the retarded citizen's rights are often lost by default.

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[163] See Civil Rights of Institutionalized Persons: Hearings on S. 1393 Before the Subcomm. on the Constitution of the Senate Comm. on the Judiciary, 95th Cong., 1st Sess. (1977). On November 15, 1977, S. 1393, as amended, was favorably reported out of the Subcommittee by a vote of 4-0.

[164] *Id.* at 9 (Statement of Drew S. Days III, Assistant Attorney General, Civil Rights Division, Department of Justice).

A. Traditional Models: Legal Formalism & Legal Abdication

The legal profession has a sorry history in defending the rights and interests of the retarded. Traditionally, people were admitted to mental retardation institutions with only perfunctory investigation of the alternatives to segregated confinement.165/ Those subject to involuntary commitments were sent off to long-term or life time confinement, without ever receiving the assistance of a partisan counsel.166/ "Voluntary" admissions, often involving serious conflicts of interest, were products of bilateral negotiations between the mentally retarded person's custodians and the

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165. Permanent, life time segregation of the mentally retarded was strenuously urged by many of the leading early 20th century professionals in this field. Dr. Walter E. Fernald, a sponsor of many of the laws relating to this movement, stated:

> A feeble-minded child is a foreign body in a family or a modern American community. It is a public duty to relieve these families of their unbearable burden. . . . Feeble-minded children may be tolerated, but it is a great responsibility to inaugurate any plan on a large scale which does not withdraw the defective adult from the community. It does not seem probable that American public opinion will be satisfied with any substitute for some form of permanent segregation of the great majority of this demoralizing class under government supervision and at State expense. W. E. Fernald, "Care of the Feeble-Minded," Proceedings of the National Conference of Charities and Corrections 380 (1904).

166. In one typical institution, the average stay was 21 years, and the average age of residents was 31. Approximately half the residents have been committed by a court. There is no distinction, however, in services made available to either court-committed or parent-admitted residents. Halderman v. Pennhurst State School and Hospital, 446 F. Supp. 1295, 1302 (E.D. Pa. 1977).

institution's administration.[167] In either situation, the prospective resident had no opportunity to participate in this decision-making or to have an independent advocate.

In other largely formalistic rituals, the "alleged retardate" could be placed under guardianship,[168] involuntarily sterilized[169] or otherwise stripped of basic rights and freedoms.[170] Even where legal counsel was

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167. On the conflicts of interest which may arise between guardian and ward in such situations, see *Institutionalized Juveniles* v. *Secretary of Public Welfare*, C.A. No. 72-2272 (E.D. Pa. May 25, 1978), *Bartley* v. *Kremens*, 402 F. Supp. 1039 (E.D. Pa. 1975), vacated and remanded 431 U.S. 119 (1977); *J. L.* v. *Parham*, 412 F. Supp. 112 (M.D. Ga. 1976); (three-judge court), *Saville* v. *Treadway*, 404 F. Supp. 430 (M.D. Tenn. 1974); *Horacek* v. *Exon*, 357 F. Supp. 71, 74 (D. Neb. 1973); *New York State Ass'n for Retarded Children* v. *Rockefeller*, 357 F. Supp. 752, 762 (E.D.N.Y. 1973). See Elkin, "Reaction Comment," 87, 89-92, in *Mentally Retarded Citizen*, *supra* note 148; Ellis,"Volunteering Children: Parental Commitment of Children to Mental Institutions," 62 *Cal. L. Rev.* 840 (1974); Herr, "Civil Rights, Uncivil Asylums and the Retarded," 43 *U. Cin. L. Rev.* 679. 718-25 (1974).

168. For discussion of guardianship as a potential instrument of "repression and dehumanization," see Kindred, "Guardianship and Limitations Upon Capacity," in *Mentally Retarded Citizen*, *supra* note 148, at 63, 87 (1976); A. Mitchell, *The Objects of Our Wisdom and Coercion* (Research Institute on Legal Assistance, unpublished paper, 1978). The President's Committee on Mental Retardation has condemned most states' provisions for guardianship as "relics, which largely consider or assume the retarded person to be without rights, deny him due process of the law,... and (otherwise) damage... retarded individuals who are capable of self-support and self-reliance." PCMR; *MR 70: The Decisive Decade* at 22 (1971).

169. See *Cavitt* v. *Nebraska*, 182 Neb. 712, 157 N.W. 2d 171, rehearing denied, 183 Neb. 243, 159 N.W. 2d 566 (1968), appeal dismissed, 396 U.S. 996 (1970) (Statute making sterilization compulsory as a prerequisite to discharge or parole from the state's institution for the mentally retarded, upheld as constitutional; ordered that resident not be released unless she is sterilized, reasoning that "the choice is hers.") See also, *Relf* v. *Weinberger*, 372 F. Supp. 1196 (D.D.C. 1974); *Wyatt* v. *Aderholt*, 368 F. Supp. 1383 (M.D. Ala. 1973).

170. R. Newman (Ed), *Institutionalization of the Mentally Retarded: A Summary Analysis of State Laws Concerning Admission of Residential Facilities and Legal Rights and Protections of Institutionalized Patients* (George Washington Institute of Law, Psychiatry and Criminology 1967).

required, the appointment of a lawyer untrained and uninterested in this task could make a sham of the right to counsel.[171] An empirical study of judicial admissions procedures described institutionalization hearings as follows:

> Court appointment of an attorney for the alleged retardate is required by statute in two of the states but observations and interviews with the attorneys and judges indicate that these attorneys do not participate in the hearing in any way. Their sole function seems to be to see that the forms required by statute are in proper order. Attorneys did not represent the retardate or applicant in the cases examined in other jurisdictions and interviews with court personnel indicated that these attorneys appear only rarely in retardation cases.[172]

The hallmark of those proceedings was the rubber-stamp approval of the petitioner's application. The judge seldom saw the person committed to the state school.[173] As a general rule, petitioners were relatives, social welfare agencies, probation officers or assistant attorneys general.[174] More often than not, the subject of petition was a child rather than an adult.[175] The proceedings bore little or no relationship to a normal judicial hearing;[176] they were paper transactions posing no real protection for the alleged mentally retarded person. This is how it worked in one urban county:

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[171] Kay, Farnham, Karren, Knakel & Diamond, "Legal Planning for the Mentally Retarded: The California Experience," 60 Cal. L. Rev. 438, 460 (1972) (counsel never present at commitment hearings according to 38 of 40 California state judges; deemed unnecessary and inappropriate by majority of judges).

[172] R. C. Allen, E. Z. Ferster & T. F. Courtless, Equal Justice for the Unequal: The Mentally Retarded and the Law, (unpublished research paper, National Institute of Mental Health Project Grant MH-01947, 1968) (Prepared by the staff of the Institute of Law, Psychiatry and Criminology, the George Washington University, Washington, D.C.), Chap. 4 at 15-16.

[173] Id. at 16.

[174] Id. at 13.

[175] Id. at 13-14.

[176] Id. at 16.

> . . . the applicant selects the physicians who are to examine the alleged retarded person. The court records showed that all petitions which were accepted by the hospital, were found suitable for commitment by the physician. There is no hearing. The physician's report is presented to the judge who always signs it.177/

Legal formalism remains very much in evidence in the mental retardation field. Stump v. Sparkman, recently decided by the United States Supreme Court, reveals the ease with which a teenager "considered to be somewhat retarded" could be sterilized without her consent.178/ It is also a stark reminder that a judicially approved sterilization and a lawyer acting for a parent offers no assurance that adverse interests will be identified or injustice averted.179/ Similar problems plague institutionalization processes, where conflicts of interests are seldom surfaced and appeals, habeas corpus writs, or administrative petitions are rarely filed.180/

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177. Id. at 18.

178. 552 F. 2d. 172 (7th Cir. 1977), Rev'd _____ U.S. _____ (1978), 46 U.S.L.W. 4253.

179. "The Volatile Issue of Sterilization Abuse: A Tangle of Accusations and Remedies," The New York Times, Dec. 9, 1977 at B. 14, col. 1. For remedial proposals, see 42 F.R. 62718 (Dec. 2, 1977); (proposed HEW regulations would require, inter alia, a 30 day interval between signing of informed consent and operation and physician's statement in writing that risks and benefits of sterilization were explained); Mass. Gen. Law (H-5975, enacted Oct. 1977) (No physician shall perform, except in an emergency, a sterilizing operation without "a knowledgeable consent" in writing from such individual, on pain of a $10,000 fine).

180. For cases which surface those conflicts, see note 167 supra. See also Bauer v. Mandel, No. 22871 (Md. Cir. Ct., Anne Arundel Cty, filed 1976), reported at 9 Cl. Rev. 903 (1976) ¶17,632 (class action challenging admission and retention procedures for state facilities for mentally retarded persons as violative of due process on their face and as administered; perfunctory hearings of as many as 15 cases in a two hour period).

Courts never explicitly articulated a "hands-off" doctrine[181] in the mental disability field. A legacy of undue judicial deference to medical authority, however, produced a similar result.[182] A parent of a retarded child, recalling her son's commitment, described the county court proceeding as "not meaningful," "not addressing the right issues," "zero protection for David," and "just tedious."[183] One Mercer County, New Jersey judge was reported as not even scheduling hearings. On the first Monday of each month, he would routinely sign the commitment forms, which his clerk would lay before him with the signature line conveniently exposed. Another New Jersey judge in Cape May County who always approved commitment papers explained that he knew all the medical doctors who made out the certificates, and that they were all friends of his.[184] For the mentally retarded person without an estate, many judges and court personnel viewed commitment proceedings simply as a waste of time. Indeed, such legal proceedings, by lending the imprimatur of due process, might have been worse than none at all. Certainly, if judges and lawyers of today were to adhere to the safeguards of commitment laws and to the canons of zealous advocacy, no one should be committed to a massive state retardation institution.185/

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[181] On the demise of the hands-off doctrine, see Note: "Beyond the Ken of the Courts," 72 Yale L. J. 506 (1963); Note: "Confronting the Conditions of Confinement: An Expanded Role for Courts in Prison Reform," 12 Harv. C.R.-C.L.L. Rev. 367 (1977).

[182] See, e.g., Jenkins v. Cowley, 384 F. Supp. 441 (N.D. Tx. 1974), (court reluctant to interfere with decisions of medical authorities in the operation of state mental hospital absent full factual showing of violation of Federal or state constitutional rights). See, e.g., In re Thaw, 143 N.Y.S. 854, 857, 158 App. Div. 571 (A.D. 2nd Dept., 1913); 7 C.J.S. Asylums Sec. 5(a) (1937).

[183] Interview with Dr. Elizabeth Boggs, former president of the National Ass'n for Retarded Citizens, in Washington, D.C. (Aug. 23, 1977).

[184] Id.

B. The Test Case Model

The civil rights movements of the 1960's uncovered patterns of systematic discrimination against persons deemed retarded.186/ Many public officials -- from school superintendents to welfare workers -- viewed the label "mentally retarded person" as a virtual warrant to provide no services or inferior services to the person so marked.187/ While the President's Panel on Mental Retardation had deplored that discrimination,188/the Panel's positive principles were largely ignored until those principles "began to be

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185. See Stamus v. Leonhardt, 414 F. Supp. 439 (S.D. Ia. 1976). (Constitutional commitment statute requires that less restrictive alternatives be considered before full-time institutionalization can be ordered); Goldy v. Beal, 429 F. Supp. 640, (M.D. Pa. 1975), (commitment standards of persons "in need of care and treatment" because of "mental disability" are void for vagueness); Institutionalized Juveniles v. Secretary of Public Welfare, C.A. No. 72-2272 (E.D. Pa. June 14, 1978) (Broderick, J. Dissenting), Slip. Op at 5 (questioning any involuntary commitment for mentally retarded persons).

186. See, e.g., Hobson v. Hansen, 269 F. Supp. 401, 507-08 (D.D.C. 1967), aff'd sub nom. Smuck v. Hobson, 408 F. 2d 175 (D.C. Cir. 1969) (tracking system which adversely affected the educational opportunities of disadvantaged minorities ordered abolished).

187. See President's Committee on Mental Retardation (hereinafter PCMR), Placement of Children in Special Classes for the Retarded (1971); PCMR, The Six-Hour Retarded Child (1970); Task Force on Children Out of School, The Way We Go to School: The Exclusion of Children In Boston (1970); Children's Defense Fund, Children Out of School in America (1974); T. Cottle, Barred From School: Two Million Children! (1976); Herr, "The New Child Savers," 12 Harv. Civ. Rts. Civ. Lib. L. Rev. 491 (1977).

188. President's Panel on Mental Retardation, National Action to Combat Mental Retardation (GPO 1962); President's Panel on Mental Retardation, Report of the Task Force on Law at 41 (GPO 1963): "When dealing with mental retardation, the law must combat many years of general ignorance, prejudice and superstition. Only when these are defeated can the law consolidate the gains in knowledge which have been made in our time."

interpreted through case law."189/ That early case law, in large measure a product of the OEO-funded legal services movement, drew upon the back-up support services described by one panel member as "the nuclei of expertise and the repositories of coordinative information."190/

Early decisions protecting the legal rights of the retarded were isolated occurrences.191/ Legal services for institutionalized persons were a rarity rather than a rule.192/ Writing in 1970 of the "Legal Dilemmas of Mental Retardation," commentators urged legal aid lawyers to assist in finding solutions to those dilemmas through "practical advocacy," "not . . . only in the courtroom but in social change."193/ These exhortations, however, failed to specify ways for legal services lawyers to coordinate with consumer organizations capable of giving content and direction to that advocacy and change.

The early cases signalling new legal protections for mentally retarded

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189. Boggs, "The Rights of the Retarded - Who's Listening?" 11 J. of Clinical Child Psychology 13 (1973).

190. Id.

191. See, e.g., Diana v. California State Bd. of Educ., Civil No. C-70-37 RFP (N.D. Cal., Feb. 5, 1970) (unreported consent decree, June 18, 1973) (new placement procedures and tests ordered for Spanish-speaking students placed in classes for the retarded after low scores on English language intelligence tests); Stewart v. Phillips, Civil No. 70-1199-F (D. Mass. Feb. 8, 1971) (reforms of educational assignment practices for school-age children classified as retarded); Frazier v. Levi, 440 S.W. 2d 393 (Tex. Ct. Civ. App. 1969) (parent cannot compel a retarded child to undergo sterilization).

192. See, e.g., Heryford v. Parker, 396 F. 2d 393 (10th Cir. 1968).

193. Inker and Perretta, "Legal Dilemmas of Mental Retardation." in N.R. Bernstein (Ed.), Diminished People: Problems and Care of the Mentally Retarded 107, 121 (1970): Attorneys in poverty law offices should be made more aware of the fact that retardates inhabit their community and need special help and patience. Professionals should willingly assist these attorneys to understand better the life patterns and activities of their clients.

persons had an almost accidental quality. Heryford v. Parker,194/for example, decided by a Court of Appeals in 1968, held that a mentally deficient youngster had a right to counsel in commitment proceedings. Yet, that case was filed over a decade after Parker's commitment and only after the state sought to recall him from home leave. Jackson v. Indiana,195/the Supreme Court's initial foray into substantive due process in civil commitments, arose not on the retarded detainee's affirmative motion, but on a competency to stand trial determination. Pennsylvania Ass'n for Retarded Citizens v. Pennsylvania, 196/a right to education case, began after the PARC Board of Directors, shocked by slides of dead children at Pennhurst State School, decided to go forward with litigation. Mills v. Board of Education,197/ ultimately securing rights to specialized education for mentally retarded and other handicapped children, was first conceived as a class action to halt arbitrary school exclusions affecting all District of Columbia children. Wyatt v. Stickney,198/on its way to becoming a right to treatment/habilitation case, first came to court when mental hospital employees sought to prevent staff layoffs.

Many years lapsed before analogous precedents in the juvenile, prison, and mental illness fields199/ were applied to retarded clients. Appellate

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194. 396 F. 2d 393 (10th Cir. 1968).

195. 406 U.S. 715 (1972).

196. 334 F. Supp. 1257 (E.D. Pa. 1971), 343 F. Supp. 279 (1972).

197. 348 F. Supp. 866 (D.D.C. 1972).

198. 344 F. Supp. 387, 344 F. Supp. 373 (M.D. Ala. 1972), aff'd sub nom. 503 F. 2d 1305 (5th Cir. 1974).

199. Halpern, "The Right to Habilitation: Litigation as a Strategy for Social Change," in The Right to Treatment for Mental Patients 73 (S. Golann & W. Fremouw, eds, 1976).

decisions which seemed to be harbingers of sweeping change were narrowly construed.200/ Considerable time passed before "right to treatment" and "least restrictive alternative" doctrines were urged on behalf of mentally retarded inmates. Even cases directly involving retarded persons, such as Heryford, practically disappeared from view.201/ While law and psychiatry became a "glamour field" for legal education and scholarship, the problems of other disabled persons in the late 1960's received short shrift from the courts, commentators and public interest practitioners.202/

By 1972, lawyers began to open a new Pandora's box of affirmative litigation. Newspapers, magazines and investigative reporters had chronicled the Dickensian horrors visited upon America's confined retarded.203/ Sometimes those reporters were one step ahead of the lawsuits; sometimes they followed in their wake.204/ At conferences and in articles, legal advocates

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200. See, e.g., Rouse v. Cameron, 373 F. 2d 451 (D.C. Cir. 1966); Lake v. Cameron, 364 F. 2d 657 (D.C. Cir. 1966), on remand 267 F. Supp. 155 (D.D.C. 1967).

201. 396 F. 2d 393 (10th Cir. 1968). Although the court expressly ruled that its right to counsel ruling had retroactive effect and suggested that it might result in "wholesale release" from confinement of retarded inmates, wholesale activity never materialized. Id. 397.

202. For pioneering exceptions, see G. Dybwad, Challenges in Mental Retardation 210 (1964) (observing that insufficient attention had been given to the legal status of the mentally retarded child and adult); tenBroek, "The Right to Live in the World: The Disabled in the Law of Torts," 54 Cal. L. Rev. 841 (1966); tenBroek & Matson, "The Disabled and the Law of Welfare," 54 Cal. L. Rev. 809 (1966). See also, Hinkle, "Legal Rights of the Mentally Retarded," 63 Amer. J. of Mental Deficiency 501 (1958).

203. Media reports of abuses of retarded residents are depressingly common. See Goodman, "The Constitution Versus the Snakepit: How Lawyers are Proving that Mental Inmates Have a Right to Treatment," N.Y. Times, March 17, 1974 (Magazine at 21); Editorial: "The Legal Rights of the Retarded," Washington Post, Mar. 15, 1973 at A18; "Retarded Girl's Care Denounced in Court," N.Y. Times, Jan. 12, 1978 at 39, col. 1; "Three Died in Seculsion, M.D. Says; Boston State Hospital Suit," Boston Globe, Jan. 19, 1978, at 3.

204. See, e.g., G. Riveria, Willowbrook (1973); K. Wooden, Weeping in the Playtime of Others: America's Incarcerated Children (1976).

for retarded persons warned that Willowbrook and Partlow were only the tips of icebergs of social neglect.[205]

The early cases put the public and the legal profession on notice of the national disaster in mental retardation care. They generated momentum for remedial national and state legislation. Federal laws, such as the Developmentally Disabled Assistance and Bill of Rights Act,[206] the Education for All Handicapped Children Act[207] and the Rehabilitation Act,[208] drew upon the logic and findings of *Mills*, *PARC* and *Wyatt*. These laws, attempts to implement constitutional rights without state-by-state litigation, were a response to advocates' pleas for "national action to resolve the problems raised in the education suits."[209]

At the state level, new statutory entitlements were created. In California, Florida, Michigan, Minnesota, New York, Ohio and elsewhere consumer coalitions and their lawyers began to overhaul the obsolescent

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205. See generally, Practicing Law Institute, *Legal Rights of the Mentally Handicapped*, Vol. 1 (B. Ennis & P. Friedman, eds, 1973; Murdock, "Civil Rights of the Mentally Retarded: Some Critical Issues," 48 *Notre Dame Lawyer* 133 (1972); Herr, "Civil Rights, Uncivil Asylums and the Retarded," 43 *U. Cin. L. Rev*. 679 (1974); Mason & Monolascino, "The Right to Treatment for Mentally Retarded Citizens: An Evolving Legal and Scientific Interface," 10 *Creighton L. Rev*. 124 (1976).

206. 42 U.S.C. Sections 6001-6081 (Supp. 1976).

207. 20 U.S.C. Sections 1401-1406, 1411-1420 (Supp. 1976).

208. 29 U.S.C. Sections 701-794 (1975).

209. Herr, "The Right to an Appropriate Free Public Education," in *Mentally Retarded Citizen*, *supra* note 148, 252, 267, (1976). Legislative history for the Education for all Handicapped Children Act, for example, is replete with references to the constitutional obligation to provide specialized education articulated by the *Mills* and *P.A.R.C.* cases.

statutory framework for mental retardation services.210/ "Residents' Bills of Rights," no less than existing Federal and state constitutional bills of rights, however, begged several questions. If enforced, those statutory rights would prevent the institutional mishandling of retarded persons. But who was there to monitor, let alone enforce those rights? For retarded residents unable to identify violations or to assert rights, problems of non-compliance were particularly acute.

Test cases generated valuable documentation as to the workings of closed institutions. Attorneys learned how poorly the bureaucracies entrusted with the care and treatment of mentally retarded persons were functioning.211/ Few institutions, for example, had formulated any policies or procedures for dealing with residents' grievances, for aiding residents in the exercise of their rights, or for safeguarding their interests in transfer and other placement or classification decisions.212/ State departments had done little

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210. See, e.g., The Lanterman Developmental Disabilities Service Act, Cal. Ann. Health & Safety Code Sections 38000-38300 (West 1973); Bill of Rights for Mentally Retarded Individuals, Ohio Rev. Code Ann. Sec. 5123.94 (Page Supp. 1974); Prohibition of Discrimination Against Handicapped Persons, Fla. Stat. Ann. Sec. 13.201(2) (West Supp. 1978); Bill of Rights of Retarded Persons, Fla. Stat. Ann. Sec. 393.13 (West Supp. 1978); Vermont H. 652 (1978), Vermont S. 103 (1977). For further discussion of legislative advocacy, see Section G. infra.

211. Professionals working with mentally retarded persons often freely acknowledged the destructiveness of current service systems and their acquiesence in those systems. "We professionals glibly condemn the service delivery system and organized structures, and at times perceive it as an adversary for its failure to provide the quantity and quality of services that are so urgently needed for the mentally retarded. As part of that system to what extent have we attempted to speak out against the inequities perpetrated against the retarded in that system? Have we demanded that the system cease and desist any activities that stultify, or demean the retarded?" Advocacy for the Legal and Human Rights of the Mentally Retarded 4 (R. Segal ed. 1972) quoted in Schoenfeld, "Human Rights for the Mentally Retarded: Their Recognition by the Providers of Service," 4 Human Rights 31, 37 (1974).

212. HEW regulations now impose some regulations detailing personal rights of retarded residents in intermediate care facilities reimbursed under Medicaid. 45 C.F.R. Secs. 249.12(a)(1)(ii).

coherent planning to develop community settings and after care service for ex-residents.[213] As a result, almost any litigation on behalf of residents became a test case in two senses: almost no case law existed directly on point, and administrators and lawyers often had to invent new policies and practices to resolve client problems.

Test case approaches had serious limitations for institutionalized clients. Cases like Heryford or Wyatt or Mills did not simply require some rule change or interpretation of statute or policy more favorable to clients' interests. The problems they exposed were not transitory, but were the problems of clients burdened with cumulative layers of disadvantage and discrimination.[214] Their problems required not surgically precise legal strikes, but on going ground warfare. Indeed, no higher court decision could possibly, in and of itself, resolve the intractable institutional problems which have troubled coalitions of lawyers, consumer groups, politicians and professionals.[215] As Chief Judge David L. Bazelon, author of many of the leading mental disability law opinions, observed: "While we generals are designing inspiring new insignia for the standard, the battle is being lost in the trenches."[216] If appellate decisions raised expectations for change, a walk through the back-wards of any major American mental institution showed how limited were the changes.

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[213] See generally, Ensminger & Reilly, "The Legal and Social Significance of Aftercare Systems: A Review and Analysis," J. of Psychiatry & L. 229 (Summer 1977).

[214] They were also problems requiring legislative cooperation in the financing of essential remedies. See Note: "Problems of Enforcing the Rights of the Mentally Retarded," 48 Notre Dame Lawyer 1314 (1973).

[215] For proposals for compliance machinery to enforce rights of the mentally disabled, see Herr, "Rights into Action: Protecting the Human Rights of the Mentally Handicapped," 26 Cath. U. L. Rev. 203, 308-18 (1977).

[216] Bazelon "Psychiatrists and The Adversary Process," 230 Scientific American 18, 21 (1974), also quoted in U.S. v. Brawner, 471 F. 2d 969 (D.D.C. 1972).

C. Legal Advocacy for Mentally Retarded Persons: A National Profile

Even today, only a few thousand retarded persons receive any direct civil legal services. From interviews, conferences, field observations and questionnaire findings, one conclusion is inescapable: all forms of advocacy assistance - whether legal, lay or otherwise - are woefully underfunded. As a result, that assistance is more frequently discussed than implemented.[217]

Some psychiatrists speak of the mental disability field as engulfed by a "flood of litigation."[218] Particularly for mentally retarded persons in custodial dead-ends, the imagined flood is scarcely a trickle. Next to a near zero baseline, any number of cases for retarded clients can be perceived as a significant increase in judicial activity. Moreover, a relatively few well-publicized cases have sent shock waves through a dormant service delivery field, with Federal cases constituting what one critic terms "the most important development in the quality of life in state institutions for the past 10 years."[219] Beyond major impact litigation and a few heroic advocacy projects, legal activity for retarded persons drops off sharply. By any absolute standard, legal services for mentally retarded citizens are in scarce supply.

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[217] On the paucity of individual legal representation, see Cohen, "Advocacy" The Mentally Retarded Citizen, supra note 148, at 591, (1976). On citizen and other forms of lay advocacy, see Institute for Research and Development in Retardation, Report to the Developmental Disabilities Council of Pennsylvania: Information and Recommendations Relating to Implementation of Title II, Section 113 of the Amended Developmental Disabilities Act of 1975 at 28 (1976), (fewer than 5,000 one-to-one citizen advocacy relationships between volunteers and retarded persons in the entire country).

[218] See, e.g., Civil Rights of Institutionalized Persons; Hearings on S. 1393 before Subcomm. on the Constitution of the Senate Comm. on the Judiciary, 95th Cong., 1st Sess. 397 (1977) (Testimony of Dr. Alan A. Stone, currently President, American Psychiatric Association).

[219] Id. at 400.

Only a handful of attorneys regularly provide legal assistance in this field.220/ In the entire country, as few as six programs maintain full time legal advocacy projects for residents of mental retardation institutions.221/ It is a tribute to their talents, energy and devotion that so few have accomplished so much. With virtual unanimity, questionnaire respondents stressed the critical shortage of people to carry out legal advocacy for retarded people. Even in the unique legal services project which serves five residential institutions for the retarded, an experienced project attorney observed:

> We have one attorney and one paralegal for an institutionalized population of 3,500. We spend half our time depressed over how little we can do.222/

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220. Only 28 attorneys reported providing services to 5 or more mentally retarded clients per month. These questionnaire results are based upon a small-scale survey of legal services offices and of persons with prior interest in legal services for mentally retarded persons. Approximately 200 questionnaires were distributed, one half to legal services programs (with every state receiving at least one) and one half to participants in the President's Committee on Mental Retardation Conference on the Future of Legal Services for the Mentally Retarded. One hundred questionnaires were returned, providing the data summarized in the Appendix and Sections III and V.

221. Institutional Legal Services Project, Evergreen Legal Services, Seattle, Washington; Comserv. Legal Representation Center, Los Lunas Training School, Los Lunas, New Mexico; Mental Health Advocacy Project, Fairview State Hospital, Orange County, California; New Jersey Department of the Public Advocate, New Lisbon Training School, New Lisbon, New Jersey; Ohio Legal Rights Service; New York Mental Health Information Service. Vermont Legal Aid expects to start such a project soon at Brandon State Training School.

222. Questionnaire No. 29, 10. (Linda Potter, Staff Attorney, Institutional Legal Services, Project/Mental Retardation Component). Since then, the Project has filed Washington Association for Retarded Citizens v. Thomas, No. C-78-163 (E.D. Wash. Filed June 16, 1978), which seeks the phasing-down of all five institutions and their replacement by the most home-like community living settings.

An increasing number of attorneys now do some work in the mental retardation field. Five years ago less than a dozen lawyers constituted the mental retardation bar.[223] Since then, the number of lawyers devoting a substantial part of their time to legal advocacy for mentally retarded persons has increased some five-fold. A still larger number has expressed interest in taking client referrals or otherwise representing retarded persons in the future.[224] Assistance, however, will not materialize without outside aid and coordination -- a specialist back-up center, training seminars, resource materials, consultation and the like.[225]

Need dramatically outstrips advocacy resources. Even with new additions to their ranks, advocates barely scratch the surface of priority mental retardation issues. Three-fourths of those responding to the questionnaires report an inability to represent all mentally retarded persons who seek their services.[226] With limited outreach and staff, programs are unable to represent all such potential clients who need legal assistance.[227]

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[223] At the 1972 annual meeting of the American Association on Mental Deficiency, an attorney who addressed a forum on law and mental retardation observed:

> You have to realize that each of you out there represents an organization with thousands of members professionally or personally interested in mental retardation, but there are only a dozen attorneys here and they constitute just about all of the country's MR bar.

Quoted in Boggs, supra at note 189, at 14.

[224] Over three-quarters of respondents indicated a willingness to take client referrals from national or state organizations. Questionnaire finding, at 3, Q. 47 (See Appendix A).

[225] Id. at 3, Q. 49-54.

[226] Id. at 3, Q. 61.

[227] Id. at 3, Q. 62.

1. The Advocates

Who are the advocates for the mentally retarded? One hundred people responded to the questionnaire on legal advocacy for mentally retarded persons. They practiced in 37 states, Puerto Rico, the Virgin Islands and the District of Columbia. Their experience included work in a wide variety of legal settings: neighborhood offices (43%), law reform units (28%), public interest firms (17%) and private practice (13%). Others were involved in mental disability legal programs (12%), law school clinics (3%) and juvenile defense offices (2%).[228] Given the small sample and their partially random and partially interest-based selection, their experience may, or may not, be typical of legal services practitioners.

The typical respondent was a legal services lawyer with four years of practice experience. While 8 had less than one year of experience, a considerable proportion were relatively experienced attorneys.[229] As expected, these attorneys' experience in legal advocacy for retarded persons is much more limited. Seventeen respondents reported no such experience, 8 less than one year, 17 between one and three years, 11 between three and five years and 20 reported five years experience or more. Only three attorneys could trace ten or more years involvement in this field.

Representing mentally retarded persons is at best a part-time, if not a sporadic concern of most attorneys. Three-fourths of the respondents have at some time represented clients with retarded mental development.230/ Slightly fewer have represented clients with other developmental disabilities (cerebral palsy, epilepsy or autism), or other disabilities (mental illness, physical impairments).231/ Sixteen percent of the responding advocates devoted half or more of their time to legal advocacy for mentally retarded persons. Another quarter spent no time, an eighth spent between 25-49% of their time and the remainder spent between 1 and 24% of their time in such advocacy.232/ Only one attorney reported devoting full time to the legal rights of mentally retarded persons. In contrast, 16 respondents identified themselves as full-time attorneys working in the mental disability field.

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[228] Respondents held a diversity of positions, including court-appointed monitor, law professor, volunteers with Associations for Retarded Citizens, judge, citizens advocate, HEW-funded technical assistance specialists, national consumer organization executive director, NIMH legal specialist, Legal Services Corporation support center attorney, U.S. Justice Department trial attorney, ACLU project director, developmental disabilities advocacy system director and state mental health information service director.

[229] Questionnaire findings at 1, Q. 3-4. Over half had 5 or more years experience; 11 of these had 10 or more years experience.

2. The Programs

The nation's advocates for mentally retarded persons are scattered across a wide spectrum of predominantly small, publicly funded projects. For the most part, providing legal assistance to the retarded is an activity done in conjunction with other project responsibilities. There are several types of specialist legal advocacy programs: projects based in, but not financed by Legal Services Corporation field programs;233/ elements of section 113

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230. *Id.* at 2, Q. 31.

231. *Id.* at 2, Q. 32.

232. *Id.* at 2, Q. 35-36.

233. The same project may receive several sources of funds. The Vermont Developmental Disabilities Advocacy Project, for example, is based in Vermont Legal Aid and has received funds as an HEW section 113 advocacy system and as an ABA bar funding project. For a full discussion of the Minnesota Developmental Disabilities Advocacy Project and references to other legal services based projects in Massachusetts, California, New York, Rhode Island and Washington State, see S. Herr, *Advocacy under the Developmental Disabilities Act*, 17-25, 45, 52-54, 65, 72-73, (1976).

advocacy systems supported by HEW's Developmental Disabilities Office;234/ public interest law firms;235/ bar sponsored legal advocacy projects for the mentally disabled;236/ state funded entities;237/ HEW funded demonstration and

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234. For legislative history and policy on implementing these systems, see Herr, id. at 5-16; Georgetown University Health Policy Center, Protection and Advocacy Systems for the Developmentally Disabled (G. Clarke & J. Stearns eds. 1977). Projects affiliated with legal services programs were designated as section 113 systems in Delaware (Community Legal Aid), Minnesota (Central Minnesota Legal Services), Louisiana (New Orleans Legal Assistance Corporation). Section 113 systems arranged for contracts for legal services in Illinois (consortium of 5 legal services programs) and Georgia. Additional information on those legal advocacy projects is collected in S. Herr, Creating Advocacy Projects for Developmentally Disabled Persons (1977) and ABA Comm'n on Mentally Disabled, Directory of Section 113 Systems (1977)

235. Among the most active in this field are the Mental Health Law Project (Washington, D.C.), the Public Interest Law Center of Philadelphia, the Children's Defense Fund, (Washington, D.C.), the National Center for Law & the Handicapped (South Bend, Ind.), the Education Law Center (Newark, N.J.).

236. Current ABA supported projects include legal advocacy projects with LSC programs as parent organizations (Georgia Mental Disability Law Project, Inc. & Vermont Developmental Disabilities Advocacy Project); a unique legal services project focusing on former residents of state mental facilities (Legal Services for the Mentally Disabled of Uptown Chicago); a legal services based project on grievance mechanisms for mental patients (Patient Grievance Procedure Project, Rochester, NY); privately funded bar-created projects providing legal services to patients and retardation institution residents (Mental Health Advocacy Project, Los Angeles & Legal Services for Mental patients, Raleigh, N.C.); and a project for released mental patients (Community Law Project, N.J.); and for increased awareness of mental health law (Colorado Bar Office for the Mentally Disabled). Interview with Lane Porter, staff member of ABA Comm'n on the Mentally Disabled, in Washington, D.C. (Nov. 25, 1977).

237. See, e.g., Ohio Legal Rights Service, Ohio Rev. Code, Sec. 5123.94; New Jersey Department of the Public Advocate, Division of Mental Health Advocacy, NJ Rev. Stat. 52:27E-25; New York Mental Health Information Service, N.Y. Mental Hyg. Law Sec. 29.09. Descriptions of the developmental disabilities related work of the Ohio, New Jersey and New York agencies are provided in Herr, Advocacy Under the Developmental Disabilities Act 26-40, 59-62 (1976).

training projects;238/ and private practitioner efforts.239/ In addition, legal services attorneys handling ordinary case intake assist mentally retarded clients from time to time.240/ At present, most areas of the country lack any mental disability law project.

Many of the existing projects depend on uncertain or short-term funding sources. The American Bar Association's eight bar funding grantees, for example, will only be supported through the Edna McConnell Clark Foundation

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238. See. e.g., Mental Patients Advocacy Project of the Western Massachusetts Legal Services (NIMH grant for advocacy and training activities at Northampton State Hospital); Center for Legal Representation of Community Services for the Handicapped (Comserv) (HEW Developmental Disabilities Office national significance grant for representation of retarded residents at Los Lunas Hospital & Training School, New Mexico).

239. See, e.g., Mental Health Legal Advisors Committee, Mass. Gen. Laws Ann. ch. 221, Sec. 34E (West 1975 Supp.), discussed in Herr, supra note 237, at 50-51. (part-time field counsel in 6 state mental health and retardation facilities; recruits panel of lawyers for compensated court-appointment). Private practitioners have had important roles in major cases, including David Ferleger (Bartley, Halderman), George Dean (Wyatt, Donaldson), Bruce Mason (Horacek) and Morton Birnbaum (Donaldson).

240. This assistance has ranged from protracted class actions (see Welsch v. Likens, 373 F. Supp. 487), (D. Minn. 1974), and cases collected at note 259 infra.) to routine poverty law problems. See, e.g., Statement of Dean Jost, supervising attorney, Legal Services for the Mentally Disabled of Uptown, Legal Assistance Foundation of Chicago:

> There are between 5,000 and 15,000 ex-mental patients living in the Uptown area of Chicago. They're usually heavily medicated, they've lived in institutions for years and years, and tend to be quite intimidated.
>
> But they are poor people like any other poor people and have consumer problems, landlord tenant problems, and probably an inordinate number of estate problems because often there will be attempts to cut them out of inheritances. There are also divorces and child custody cases.
>
> Then there are other problems... public aid and Social Security problems, problems with nursing homes, and some discrimination against the mentally handicapped. Quoted in Legal Services Corporation Annual Report 1977 at 29.

for a two-year period through 1978.241/ Other grant programs typically provide for annual renewals for no more than a three year period.242/ Reliance on foundation or governmental monies may also introduce subtle distortions of advocacy priorities and divert considerable energies from client representation. Many programs are less than a year old and are not equipped for complex advocacy on behalf of mentally retarded clients. Unlike Legal Services Corporation grantees, the newer section 113 advocacy systems sometimes encounter basic challenges to their independence. These challenges may take the form of outside attempts to discourage litigation or to impose special conditions before advocates can go beyond internal grievance procedures.243/

Well-established programs provide a full range of advocacy services for mentally retarded clients. Although class actions and other impact cases capture the greatest attention, programs report negotiation, individual representation and referral as the major modes of resolving cases. Some projects perceive a tension and separation between impact law reform work and the handling of individual cases. This attitude reinforces an unfortunate

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241. Interview with Joseph Varygas, Director, Mental Disability Legal Resources Center, ABA Com'n. on the Mentally Disabled, in Washington, D.C. (Dec. 16, 1977).

242. Telephone interview with Marianne Bennett, Director, Comserv. Center for Legal Representation (Feb. 23, 1978).

243. Telephone interview with Wallace Winter, Director, D.D. Law Project, (Dec. 5, 1977). State officials wanted institutional advocates to exhaust all "chain of command" internal grievance procedures before seeking external remedies; Governor's office rebuffed in effort to require notice to state officials 30 days in advance of filing litigation.

In California and the District of Columbia, as in many other states, there are still no direct legal services provided, and plans by Developmental Disabilities authorities suggest no real intention to do so.

sense of dichotomy between reform (seen as the province of legal organizations priding themselves as being on "the cutting edge") and service delivery (seen as the work of those "in the trenches"). Projects achieving the most satisfactory outcomes for their mentally disabled clients do both reform and individual service work and employ the full range of advocacy methods. The Western Massachusetts Legal Service's Mental Patient Advocacy Project, for example, focusing on individual representation and hospital-level redress, has found time for action seeking institution-wide relief.244/ Its attorneys converted their intimate knowledge of client needs into a deinstitutionalization class action. If successful, Brewster v. Dukakis will phase out the Northampton State Hospital and restructure the state mental care system. Similarly, developmental disability advocacy projects in Minnesota and Vermont have used litigation as a vehicle for mobilizing consumer interest and as an opening wedge toward wider administrative and legislative resolutions.245/ Due to special problems of access to mentally retarded clients,246/class actions and other forms of collective representation often precede large-scale individual representation. Properly framed, those actions

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244. Brewster v. Dukakis, C.A. No. 76-4423-F.(D. Mass, consent decree, Dec. 7, 1978). During the first quarter of 1977, the Project opened 7 new cases and closed 11 others; argued before the Appeals Court, amended its deinstitutionalization complaint in Federal court; obtained release of all 8 patients subject to hospital-initiated commitment petitions; provided group representation for a local chapter of the Mental Health Association in a zoning application for a proposed halfway house, and engaged in a variety of training workshops and related community education activities. Interview with Steven J. Schwartz, Managing Attorney, Mental Patients' Advocacy Project, Northampton State Hospital, Northampton, Mass (Nov. 8, 1977).

245. Interview with Neil Mickenberg, director of the Vermont Developmental Disabilities Advocacy Project and former managing attorney, Minnesota Developmental Disabilities Advocacy Project, in Burlington, Vermont (Nov. 7, 1977).

246. Access problems are discussed in Section IV, infra.

can open up new representational possibilities for previously isolated or unidentified class members.[247] Without a broader advocacy framework and agenda, individual representation by itself may result in the state simply shifting scarce resources from one indigent to another, or from one group of mentally retarded persons to another.[248]

3. The Clients

Cases for mentally retarded clients often begin through third-party referrals. Sources of referral may include relatives, social workers, citizen advocates or disability consumer group staff or volunteers (57% of advocates surveyed). Mildly retarded persons, guardians or mentally competent developmentally disabled persons may become program clients through walk-ins or "roll-ins" (42%). Programs also report obtaining clients through public contacts (35%) and liaison with consumer groups (31%). Given the importance of outreach to disabled persons with mobility problems, a number of advocates obtain clients by walking wards, visiting facilities (21%) and maintaining offices or sub-offices in institutions (15%).249/

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[247] See, e.g., Haney v. Parham, No. C 75-584A (ND Ga., filed March 28, 1975) 9 Clearinghouse Rev. 141 (consent decree on social services and day-care services in state training center for residents of ICF-MR facilities). This class action has led to other clients and generated individual enforcement actions for developmentally disabled residents of these facilities. Letter from Jonathan A. Zimring to author (Jan. 3, 1978). On the impact of Mills and P.A.R.C. in stimulating due process hearings for adversely affected individuals, see Kirp, Buss & Kuriloff, "Legal Reform of Special Education: Empirical Studies and Procedural Proposals," 62 Cal. L. Rev. 40 (1974).

[248] This is illustrated by the transfer of some 300 mentally retarded residents of Belchertown State School following Federal litigation challenging overcrowding and lack of treatment at that State School. Ricci v. Greenblatt, C.A. No. 72-469-F (D. Mass. March 13, 1972). Although not diagnosed as mentally ill and although appropriate for placement in community-based programs, they were moved en masse to the Northampton State Hospital. As a result, they "continue to be institutionalized in a facility that provides no suitable treatment for their mental condition." Brewster v. Dukakis, C.A. No. 76-4423-F, Plaintiffs' Memorandum in Opposition to Defendants' Motion for Abstention and Certification, at 4 (Aug. 10, 1977).

There is enormous variety in the cases handled for mentally retarded clients. Lawyers involved in individual representation reported seeing their clients, on an average, between 1 and 9 times per case, with 2 times being the most frequent response.250/ Length of initial client interview ranged from a quarter of an hour for clients described as "not too verbal" up to 5 hours.251/ Clients were most frequently described as indigent and institutionalized.252/ Nearly a quarter of the programs were mainly involved in commitment process cases. Programs were more likely to have engaged in litigation through individual representation than through class actions.

A clear division emerged between class action and individual service practitioners. Only a few attorneys have engaged in both forms of legal advocacy for mentally retarded persons. While over a third of the respondents were involved in class actions, only nine advocates said they had represented retarded persons in both individual and class proceedings.253/ Furthermore, a

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249. Appendix A, at 27. Other methods of client finding are court appointment (17%), advertising (13%), statutory or contractual authority (11%) and telephone hot-lines (7%).

250. Id. at 10.

251. Id. at 14.

252. Id. at 27-28.

An estimated 68% of all inpatients of state and county mental hospitals fall below the poverty line. Telephone interview with Dr. Richard Redick, Division of Biometry, NIMH, (July 14, 1978). Indigency of residents of mental retardation institutions is likely to be even higher, given residents' lack of employment history or clear access to their funds. The majority of these respondents' clients were further described as mentally retarded, mentally ill, juveniles, developmentally disabled and physically disabled persons.

253. Id. at 19.

disproportionately large number of mentally retarded clients have received services from a handful of attorneys and programs. Putting aside class actions, only 8 advocates had represented more than 100 mentally retarded individuals.254/ Attorneys in specialist projects, like the Minnesota Developmental Disabilities Law Project, the New York Legal Aid Society's Mental Hygiene Bureau or the Mental Health Information Service, were carrying the bulk of this reported case load.255/ Ironically, a resident of a mental retardation institution may find it easier to be a part of a Federal class action than to obtain a lawyer to defend some individualized interest.

D. Structural Class Actions

Nearly every state has one or more large, antiquated and often remote mental retardation institutions. Typically, these public facilities are not accredited256/ and isolate residents from community services and amenities.257/ In seventeen states, sweeping class actions challenge

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254. Id. at 12.

255. Respondents reported representing nearly 3,000 mentally retarded clients, 924 of whom were reported served by the Minnesota Developmental Disabilities Law Project. The total of other mentally disabled clients represented exceeded 4,316.

256. Of 1,705 facilities for the mentally handicapped, 1,595 (93%) were not accredited by any professional organization. HEW survey of Institutional Persons, "Table No. 8, Type and Size of Facility by Accreditation by Professional Organization," (Planning and Evaluation, unpublished data March 1978).

257. The literature criticizing these institutions is voluminous. See e.g., D. Braddock, Opening Closed Doors: The Deinstitutionalization of Disabled Individuals 50-74 (1977); B. Blatt & K. Kaplan, Christmas in Purgatory (1974); President's Committee on Mental Retardation, Changing Patterns in Residential Services for the Mentally Retarded (R. Kugel & A. Shearer eds. 1976); D. Vail, Dehumanization and the Institutional Career (1967); McCormick, Balla & Zigler, "Resident-Care Practices in Institutions for Retarded Persons," 80 Am. J. of Mental Deficiency 1, 14 (1975); Wolfensberger, "Will there always be an institution?" 9 Mental Retardation 14-20, 31-37 (1971).

segregated and inhumane institutional conditions.258/ Legal services lawyers have filed some of the leading omnibus suits for residents of understaffed, overcrowded and chaotic mental retardation institutions.259/

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258. Wyatt v. Stickney 344 F. Supp. 387 (M.D. Ala. 1972), subsequent citations at note 267 infra; Evans v. Washington, 459 F. Supp. 483 (D.D.C., 1978); Burnham v. Georgia, 349 F. Supp. 1335 (N.D. Ga. 1972), rev'd and remanded 502 F. 2d 1319 (5th Cir. 1974); Kentucky Ass'n for Retarded Citizens v. Conn, No. C-77-0048 (W.D. Ky., filed June 2, 1977); Gary W. v. Stewart, 437 F. Supp. 1209 (E.D. La. 1976), Wouri v. Rosser, No. 75-80-SD (S.D. Maine, filed Aug. 22, 1975); United States v. Solomon, 419 F. Supp. 358 (D. Md. 1976), aff'd 563 F. 2d 1121 (4th Cir. 1977); Ricci v. Greenblatt, No. 72-469-F (D. Mass. consent decree, Nov. 12, 1973); Massachusetts Ass'n for Retarded Citizens v. Dukakis, C.A. No. 75-5023-T, (D. Mass., Wrentham interim consent decree, July 12, 1977); Massachusetts Ass'n for Retarded Citizens v. Dukakis, C.A. No. 75-5210 (D. Mass., Dever interim consent decree, July 12, 1977); Gauthier v. Benson, C.A. No. 75-3910-T (D. Mass., Monson supplemental consent decree, July 12, 1977); McEvoy v. Stevens, C.A. No. 74-2769-M(T), (D. Mass. Fernald interim consent decree July 12, 1977); Brewster v. Dukakis, No. 76-4423-F (D. Mass., consent decree Dec. 7, 1978); Michigan Ass'n for Retarded Citizens v. Smith, C.A. No. 870384, (D. Mich., consent decree, March 3, 1978); Welsch v. Likens, 373 F. Supp. 487 (D. Minn. 1974); Caswell v. Califano, No. 77-0488 CV-W-4 (W.D. Mo., filed June 30, 1977); Doe v. Hudspeth, Civil No. J. 75-36(N), (S.D. Mass., consent decree Feb. 19, 1977); United States v. Mattson, C.A. No. 74-138 (D. Mont., Sept. 28, 1976); Horacek v. Exon, 357 F. Supp. 71 (D. Neb. consent decree, Oct. 31, 1975); New York State Ass'n for Retarded Children v. Rockefeller, 357 F. Supp. 752 (E.D.N.Y. 1973) (for subsequent citations and discussion of case, see text and notes at note 289-304); New York State Ass'n for Retarded Children v. Carey 76 Civ. 2860 (S.D.N.Y., stipulations of voluntary dismissal and settlement re: Wassaic Developmental Center, Nov. 9, 1977); Davis v. Watkins, 384 F. Supp. 1196 (N.D. Ohio 1974); Barbara C. v. Moritz, No. C 2-77-887 (S.D., Ohio, filed Nov. 17, 1977); Sidles v. Delaney, No. C 75-300A (N.D. Ohio, consent decree, April 26, 1976); Halderman v. Pennhurst State School & Hospital, 446 F. Supp. 1295 (E.D. Pa., 1977); Saville v. Treadway, 404 F. Supp. 430 (M.D. Tenn. 1974); Washington Ass'n for Retarded Citizens v. Thomas, No. C-78-168 (E.D. Washington filed June 16, 1978).

259. These include Welsch v. Likins, New York State Association for Retarded Children and Parisi v. Rockefeller, Brewster v. Dukakis, Caswell v. Califano, Davis v. Watkins, Saville v. Treadway; Kentucky Ass'n for Retarded Citizens v. Conn., Wouri v. Rosser, Doe v. Hudspeth, Washington Ass'n for Retarded Citizens v. Thomas, supra note 258. For other mental retardation cases filed by legal services attorneys, see Weidenfeller v. Kidulis, 380 F. Supp. 445 (E.D. Wisc. 1974) (peonage in private group home for the retarded, by Legal Aid Society of Milwaukee); Frederick v. Mulcahy, C.A. No. 76-257 (D. Vt., filed Dec. 16, 1976) (conditional discharge procedures from state training school alleged unconstitutional, by Vermont Legal Aid Society).

These suits can not and should not be modeled after prison conditions litigation. Given the goal of normalized living for mentally retarded persons, there can be no justification for subjecting people to life-long institutional care under conditions which are anything but normal. Unlike penal inmates, residents may not be able to aid their lawyers in drafting complaints, identifying abusive conditions, framing remedies or monitoring relief. After long years inside, even the most competent may have little or no information as to possible alternative living situations. All this places greater responsibilities on their attorneys to review post-institutional plans, to consult informed expert opinion and to avoid remedies which reify institutions. A "good resolution" of the residents' plight demands a remedy stretching well beyond the institutional walls. A narrow focus on "cleaning up" the institution would not address the deeper interests of mentally retarded clients.

"Structural class actions" attempt to change service delivery systems and to introduce some dynamic elements safeguarding the clients' interests. The new elements may consist of monitoring and compliance machinery, such as court-appointed review panels,[260] special masters[261] or human rights

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260. See, e.g., NYSARC v. Carey 393 F. Supp. 715 (1975). The Willowbrook Review Panel is described at text and notes 302-303, infra. A similar Review Panel, the Nebraska Mental Retardation Panel, was devised, but not implemented in Horacek v. Exon, 357 F. Supp. 71 (D. Neb. 1973), No. 72-L-299, Decree and Agreement of Aug. 6, 1975, at 3, 12-18, principally due to legislative opposition.

261. Masters have been appointed in juvenile care cases: Gary W. v. Stewart, No. 74-2412C, Order of Jan. 5, 1977 (E.D. La.); in special education cases: Mills v. Board of Education, No. 1939-71 (D.D.C. June 9, 1975, July 24, 1975); PARC v. Pennsylvania, 343 F. Supp. 279 (E.D. 1972); in mental institution cases: Halderman v. Pennhurst, 446 F. Supp. 1295, (E.D. Pa. 1978); Davis v. Watkins, 384 F. Supp. 1196, 1212 (N.D., Ohio 1974), No. C-73-205 (N.D., Ohio April 30, 1976); (to

committees.[262] These agents, vested with ongoing responsibilities to protect residents' rights, may compel or negotiate the enforcement of standards. A remedy might also require additional legal and citizen advocacy for individual class members.[263] These suits require more than rule changes. Successful mental retardation litigation can alter community placement policies, prohibit seclusion, detail institutional standards and expand the range and quantity of

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261. Cont'd.
"oversee the implementation of the Provisions of this Order and to resolve any dispute arising out of the interpretation of its meaning, effect or language.") Motions for the appointment of a special master are pending in Wyatt. For commentary favoring such appointment, see Note: "Implementation Problems in Institutional Reform Litigation," 91 Harv. L. Rev. 428, 459-60 (1977), Smithson, "The Special Master in Correctional Cases: A Preliminary Survey," 9 Clear. Rev. 15 (1975) See Generally, Kaufman, "Masters in the Federal Court: Rule 53," 58 Colum. L. Rev. 452 (1958); Note: "Masters and Magistrates in the Federal Courts," 88 Harv. L. Rev. 779 (1975).

[262] See, e.g., Wyatt v. Hardin, No. 3195-N (M.D. Ala. Feb 7, 1975). The Human Rights Committees did not gain full-time staff until three years after their creation. This delay and problems of access to the institution limited these citizen committees in securing enforcement of the decree. See Lottman, "Enforcement of Judicial Decree: Now Comes the Hard Part," 1 Mental Disability L. Rep. 69, 72 (1976). For a judge appointing a citizens' commission of two inmates and three outsiders to investigate a correctional facility and adopting their findings, see Barnes v. Government of Virgin Islands, 415 F. Supp. 1218, 1222-23 (D.V.I. 1976).

[263] See., e.g., Davis v. Baylor (formerly Watkins), No. C-73-205 (N.D. Ohio Sept. 1, 1976) (patients' legal advocates to assist the master in investigating institutional compliance and physical abuse incidents); Barnes v. Government of Virgin Islands, 415 F. Supp. 1218, 1235 (D.V.I. 1976) (correctional institution ordered to make office available for attorney-inmate conferences and to assist attorney in setting up the interviews for weekly visit; Legal Services of the Virgin Islands, representing plaintiff, volunteered to make an attorney available at the institution one morning a week); See also, Morales v. Turman, 364 F. Supp. 166 (E.D. Tex. 1973) (ombudsman ordered for juvenile delinquency institutions); Morgan v. Sprout 432 F. Supp. 1130 (S.D. Miss. 1977) (access to legal services for residents of juvenile training school).

habilitation and education services.264/

The current debate centers on the locus of those services and the need for services to follow residents returning to the community. Structural class actions should question the very raison d'etre of institutional facilities. Federal class actions such as Willowbrook and Pennhurst attempt to replace large mental retardation institutions with a network of community-based services. Unlike earlier suits which sought deinstitutionalization in part and institutional reform in part, New York State Association for Retarded Children v. Carey and Halderman v. Pennhurst State School recognize the futility of institutional rehabilitation.265/ Both actions stand in marked contrast to law suits to repair institutions,266/ efforts which reinforce the regressive nexus between institutionalization and the receipt of mental retardation services.

The seminal "right to treatment" case, Wyatt v. Stickney,267/ pioneered institution-wide standard setting. Wyatt and the companion case of

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264. On the legitimacy of such judicial intervention, see Chayes, "The Role of the Judge in Public Law Litigation," 89 Harv. L. Rev. 1281 (1976); Johnson, "The Constitution and the Federal District Judge," 54 Texas L. Rev. 903, 908-14 (1976); A. Cox, The Role of the Supreme Court in American Life, 96-98 (1976). On the impact of such judicial interventions, see Note: "The Wyatt Case: Implementation of a Judicial Decree Ordering Institutional Change" 84 Yale L. J. 1338 (1975); Herr, "Civil Rights, Uncivil Asylums, and the Retarded," 43 U. Cin. L. Rev. 679 (1974).

265. See NYSARC opinions quoted and discussed at text and notes 289-304 and Pennhurst opinion discussed at text and notes 306-327.

266. See McEvoy v. Stevens, C.A. No. 74-2769-M(T), (D. Mass., Fernald interim consent decree, July 12, 1977) and other cases criticized at text and notes 334-46, infra.

267. 325 F. Supp. 781 (M.D. Ala. 1971), 334 F. Supp. 1341 (1971), enforced 344 F. Supp. 373 (1972), 344 F. Supp. 387 (1972), aff'd sub nom. Wyatt v. Aderholt, 503 F. 2d 1305 (5th Cir. 1974).

Burnham v. *Georgia* 268/ remain the law of the Fifth Circuit, and its rationale has been followed in Federal and state jurisdictions in a wide variety of mental disability269/ and juvenile cases.270/ Even the National Association

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268. 349 F. Supp. 1335 (N.D. Ga. 1972), rev'd 502 F. 2d 1319 (5th Cir. 1974), *cert. den'd*. 422 U.S. 1057 (1975). In *Burnham*, the District Court, finding no constitutional right to treatment, was reversed by the Fifth Circuit on the basis of its *Wyatt-Donaldson* decisions. Even though the Supreme Court had vacated the Fifth Circuit *Donaldson* decision only four days before, it denied *certiorari* in *Burnham*, allowing *Wyatt* with its constitutional right to treatment holding to remain as the law of the Fifth Circuit. Accord: *Halderman* v. *Pennhurst State School*, 446 F. Supp. 1295, 1316 (E.D. Pa. 1977).

269. *Halderman* v. *Pennhurst State School*, 446 F. Supp. 1295 (E.D. Pa. 1977), *Welsch* v. *Likens* 373 F. Supp. 487 (D. Minn. 1974), aff'd in part and vacated and remanded in part, sub nom *Welsch* v. *Dirkswager*, 550 F. 2d 1122 (8th Cir. 1977), Consent Decree, No. 4-72 Civil 451 (Dec. 1977); *Davis* v. *Watkins*, 384 F. Supp. 1196 (N.D. Ohio 1974); *Gary W* v. *Louisiana*, 437 F. Supp. 1209, 1219 (E.D. La., 1976), (involuntarily committed retarded, physically handicapped and delinquent children have a constitutional right "to a program of treatment that affords the individual a reasonable chance to acquire and maintain those life skills that enable him to cope as effectively as his own capacities permit with the demands of his own person and of his environment and to raise the level of his physical, mental and social efficiency"); *Saville* v. *Treadway*, 404 F. Supp. 430, 433 (M.D. Tenn. 1974), *Woe* v. *Matthews*, 408 F. Supp. 419, 429 (E.D. NY 1976), remanded in part, dismissed in part sub. nom. *Woe* v. *Weinberger*, 556 F. 2d 563 (2d Cir. 1977). Mental hospital cases relying on *Wyatt*, include *Patients* v. *Camden County Board of Chosen Freeholders*, No. L 33417-74 P.W. (N.J. Super. Ct. Camden Cty, July 19, 1976) text reprinted in full, 1 Mental Disability L. Reporter 188, 10 Cl. Rev. 645 (1976) #Cl. 19,311 (committed persons constitutionally entitled to "adequate treatment in the least restrictive environment"); *Rone* v. *Fireman*, No. 75-355A (N.D. Ohio May 3, 1976) (stipulation to preliminary injunction prohibits further admissions until requirements for staffing, sanitation, fire safety and patient examination and placement are met).

270. *McRedmond* v. *Wilson*, 533 F. 2d 757 (2d Cir. 1976); *Nelson* v. *Heyne*, 355 F. Supp. 451, 459 (N.D. Ind. 1972), aff'd 491 F. 2d 352, 358 (7th Cir. 1974), cert denied, 417 U.S. 976 (1974); *Pena* v. *New York State Division for Youth*, 419 F. Supp. 203, 207 (S.D., N.Y. 1976); *Inmates of Boys' Training School* v. *Affleck*, 346 F. Supp. 1354, 1372 (D. R.I. 1972); *Stachulak* v. *Coughlan*, 364 F. Supp. 686 (N.D. Ill. 1973); *Morgan* v. *Sprout*, 432 F. Supp. 1130, 1136 (S.D., Miss. 1977). For other pending cases, see Swanger, "Juvenile Institutional Litigation," 11 *Clearinghouse Rev*. 219. n.4 (1977).

of Attorneys General has acknowledged the weight of these precedents.271/ Wyatt reveals, however, the practical and doctrinal pitfalls of focusing on institutional conditions and a right to treatment remedy which seeks their correction. Six years after the entry of Judge Frank N. Johnson, Jr.'s orders, the State of Alabama has compiled a mixed record of implementation, a record which gives short shrift to residents' community placement needs.

Much, however, has been accomplished. The Wyatt litigation, in the words of the court-appointed Human Rights Committee chairperson, brought "Alabama out of the dark ages of mental care."272/ At the time of the 1972 trial, Partlow State School and Hospital housed 2290 residents attended by 520 resident care workers under conditions described as "generally dehumanizing, fostering deviancy, generating a self-fulfilling prophecy of parasitism and helplessness."273/ Four years later, 1381 individuals were on the rolls at Partlow, of whom 1301 were "in-house" residents and 80 were on trial placements in the community.274/ In the wake of judicial orders, treatment staff had been markedly increased and Mental Health budgets expanded in what the Court in 1975 described as "steady, albeit slow, progress" toward full implementation of the constitutional guarantees enumerated in the Partlow decree.275/ Against the sweeping standards set out under that decree,

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271. National Association of Attorneys General, The Right to Treatment in Mental Health Law ii (Feb. 1976).

272. Interview with Mrs. Harriet Tillman, Chairperson, Partlow Human Rights Committee, at Airlie House, Virginia, (September 28, 1977).

273. 344 F. Supp. at 391 n.7, citing the testimony of Dr. Philip Roos, Executive Director, National Association for Retarded Citizens.

274. Defendants' Answer to Interrogatory 84, cited at Wyatt v. Hardin, C.A. No. 3195-N, "Joint Report of Plaintiffs and Amici United States, American Orthopsychiatric Association, American Civil Liberties Union, American Psychological Association, American Association on Mental Deficiency, and National Association for Mental Health Pursuant to Order Dated December 31, 1975," at 35 (M.D. Ala., filed Feb. 10, 1977). (hereinafter, "Joint Report").

275. Wyatt v. Hardin, C.A. No. 3195-N, Order of April 18, 1975 at 2. Directing defendants to prepare detailed compliance reports, Judge Johnson concluded that "a serious deficiency" in constitutionally adequate habilitation programs existed at Partlow and that "(m)eaningful and sufficient steps have not been taken to assure that each resident is

Alabama's 1977 implementation reports reveal significant areas of noncompliance. By defendants' own admissions, adult residents at Partlow received only 3.4 hours per day of habilitation programming,[276] while 40% of school-age residents received less than six hours of programming of any sort.[277] Professional staffing was only 53% of that required under the court-ordered minimum staffing standards, with severe shortages of special educators, social workers and occupational, physical and recreational therapists.[278] More than half of the residents still lived in large ward-like bedrooms of 24 or more residents, four times the permissible maximum.[279] Under Standard 3(c) of the 1972 Wyatt order, residents "have the right to the least restrictive conditions necessary to achieve the purposes of habilitation."[280] In seeming contravention of standards requiring defendants to make every attempt to move residents into less restrictive settings and to smaller facilities "integrated into community living"[281] nearly 10% of Partlow's population is mildly retarded, borderline retarded or not retarded.

Wyatt demonstrates some striking advantages and limitations of omnibus remedial decrees. As the first "right to treatment" holding decided on constitutional grounds and the only case to attack conditions simultaneously

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275. Cont'd.
accorded his 'right to a habilitation program which will maximize his human abilities and enhance his ability to cope with his environment.'"

[276] Wyatt v. Hardin, C.A. No. 3195-N, "Response of Amicus Curiae United States and Amici Associations to defendants' Brief in Opposition to Amici's Motion for Further Relief and Defendants' Motion to Dismiss or for Summary Judgment," (filed Sept. 10, 1977) at 5, n. 3.

[277] Id. at 8, n. 13.

[278] Id. at 9-10.

[279] Id. at 11.

[280] 344 F. Supp. at 387, 396 (M.D. Ala. 1972).

[281] Id. See also Standard 4 barring placement in the institution of non-retarded, borderline and mildly retarded persons. At Partlow, 118 residents were identified as mildly retarded, 8 as borderline retarded and 13 as non-retarded. In addition, 19 mildly retarded individuals are institutionalized in a satellite facility.

in state mental retardation and mental institutions, Wyatt opened up broad territory to judicial scrutiny and public exposure. Nationally, it hastened ICF-MR regulations, triggered staffing increases, raised institutional care costs to points discouraging needless admissions and heightened the public and professional consciousness of residents'/patients' rights. In Alabama, however, the case never received the continuous attention of counsel and court required of such an ambitious judicial undertaking. Human Rights Committees, the citizens' committees appointed by the Court at the three state institutions, lacked the expertise or staff to perform the complex monitoring and reporting functions envisaged by the decree.[282] Out-of-state counsel and expert consultants for the United States and professional association amici could not fully discharge these missing functions. At long distance, efforts at speeding implementation degenerated into "a paper work battle," in which few direct advocacy services were provided to individual residents. With the gradual withdrawal of plaintiffs' private attorneys from active involvement in implementation phases of the case, new resources for external advocacy were sorely needed. In an attempt to provide on-going pressure, amici have filed a motion for further relief and renewed a request for the appointment of a special master.[283]

Detailed and lengthy standards carry the risk of selective enforcement.

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[282] See Comment: "The Wyatt Case: Implementation of a Judicial Decree Ordering Institutional Change," 84 Yale L. J. 1338, 1366-67, 1371 (1975).

[283] The Wyatt Court recognized, but refrained from exercising its power to appoint a master at the time of its remedial orders. 344 F. Supp. 387, 394 (1972). The Amici's proposed order for the appointment of a special master sets out many of the powers and functions exercised by the Willowbrook Review Panel, including the power to make formal recommendations binding on the parties unless objected to and overturned by the Court as "clearly erroneous." (Proposed Order at 5) For mental disability cases ordering special masters during implementation, see note 261, supra.

Unless the parties and the court fix some priorities among competing objectives or narrow the objectives desired, state bureaucrats may distort implementation of court orders. The Alabama Mental Health Board and other defendants directed most new expenditures to restructuring the institution rather than to devising alternative methods of providing adequate care and treatment in small community-based centers. 284/ Institutional reform rather than community-based care was their primary target, with the result that treatment resources were far more available in the institutions than in nursing homes and other small group homes.285/

In Wyatt, the court's constitutional formulation stressed a global objective; i.e. fully effectuating "the constitutional right of each resident . . . to a habilitation program which will maximize his human abilities and enhance his ability to cope with his environment."286/ The 49 specific standards for achieving this right to habilitation prescribed least restrictive community placements, individualized habilitation plans, a humane environment and sufficient qualified staff to provide adequate habilitation care.

Wyatt declared a right to habilitation in the least restrictive setting. Post-institutional plans were required for each resident, with interdisciplinary team leaders responsible for carrying out those plans. Alabama defendants lost sight of those latter requirements and failed to carry out the comprehensive planning at individual and state-wide levels essential

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284. Comment: The Wyatt Case, supra note 282, at 1372.

285. Barnett, "Treatment Rights of Mentally Ill Nursing Home Residents," 126 U. Pa. L. Rev. 578, 592-602 (1978) (for 700 ex-Bryce Hospital mental patients transferred to private nursing homes living conditions may be improved, but medical and psychosocial treatment services are fewer).

286. 344 F. Supp. 387, 396 (M.D. Ala. 1972).

to meaningful compliance. Although Judge Johnson had received extensive testimony on the value of community placement for mentally retarded persons, his 1972 opinion had not emphasized this aspect of habilitation. Although the allocation for community mental retardation services increased from $360,000 in 1972 to some $3,000,000 for 1978,[287] five years after the _Wyatt_ orders the Alabama Department of Mental Health still had only 15 group homes (with a total capacity for 99 mentally retarded persons) for the entire state.[288] The Department's lack of strategic planning to develop effective community alternatives to institutionalization and the Commissioner's unwillingness to give priority to community services has frustrated the proper implementation of the _Wyatt_ decree.

The _Willowbrook_ case[289] has proved a more successful vehicle for community-based habilitation. Originally modeled after the _Wyatt_ case, it evolved in sharply contrasting ways. On March 17, 1972, when suits were filed in the Eastern District of New York, Willowbrook State School with its 5209 residents was then known as the world's largest retardation institution. The lawsuit's initial goal was to achieve "professionally recognized minimum standards of education, care, training and treatment." These services were referred to as "habilitation," a process aimed at giving each resident a realistic chance to improve his or her level of mental and physical functioning.290/ Under a protection from harm theory, plaintiffs documented the gamut of physical, psychological and social injuries suffered by institutional residents. On that record, the Court ordered a phased reduction of Willowbrook's population to 250 residents by 1981 and corresponding increases in community services. By consent decree, a well-funded, professionally staffed Review Panel was created to monitor and provide quality assurance controls regarding those community placements. The activism of the Willowbrook Review Panel and the proximity of plaintiffs' counsel to their clients meant that the remedy could be fine-tuned to changing conditions and to reports of specific implementation problems. Most importantly, the Willowbrook court has remained accessible to the plaintiffs and the Panel. Through periodic hearings and admonitions to defendants, Judge Judd and Judge Bartels had insisted their decrees become more than paper pronouncements.

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[287] _Wyatt_, Amici Response, _supra_ note 276, at 26.

[288] Defendants' Answer to Interrogatory 124, cited at Joint Report, _supra_ to note 274, at 52.

[289] _New York State Association for Retarded Children and Parisi_ v. _Carey_ (formerly Rockefeller), No. 72-C-356/357, 357 F. Supp. 752, (E.D. N.Y. 1973), 393 F. Supp. 715 (1975), 409 F. Supp. 606 (1976). Hereinafter "NYSARC" or "Willowbrook Case." The case is also reported at 6 Clearinghouse Rev. 284 (1972); 9 Clearinghouse Rev. 209 (Clearinghouse No. 7908) and subsequent unpublished orders at 1 Mental Disability Law Reporter 334 (Order of Feb. 8, 1977 & March 10, 1977); 445 (June 10, 1977).

Litigation proceeded in two stages. At hearings for preliminary injunctive relief, plaintiffs proved that Willowbrook was not even a decent custodial institution.291/ On the hearing for final relief, Willowbrook was shown to be incapable of providing its residents therapeutic or habilitative programming.292/ At the time of the suit's filing, most residents had no individualized habilitation program plan and were forced to live in an overcrowded, "anti-therapeutic environment." Improperly clothed, often left entirely naked, residents lay idle on wards giving off an "overpowering stench of sweat, urine, and human excrement."293/ Programming was shockingly lacking: 80% of the school age residents had no schooling, 96% of the

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290. Id. Plaintiffs' Brief at 1, NYSARC C.A. No. 72-356.

291. 357 F. Supp. 752 (E.D. N.Y. 1973).

292. 393 F. Supp. 715 (E.D. N.Y. 1975).

293. NYSARC, C.A. No. 72-356, Complaint at 22.

residents received no speech therapy or language development. Sanitary conditions were so grossly inadequate that almost all residents developed a hepatitis antigen in the bloodstream within six months of admission. Residents lacked any semblance of a habilitation program in the institution and had no means of getting to programs in the community.

Admission to Willowbrook was virtually a one-way ticket. Before 1972 the state was under no great pressure to develop community placements for state school residents. "Willowbrook," as the complaint put it, "is, at best a custodial warehouse, which provides them with nothing but food and shelter and a place to live until they die."294/ Indeed, staff seldom conducted periodic reviews or developed least restrictive placement plans for residents. Two-thirds of the residents had not had their intelligence re-evaluated in the preceding seven years. The cumulative impact of these conditions on the individual was disastrous. On a motion for preliminary relief, the District Court rejected the state's defenses and ordered extensive relief grounded on an Eighth and Fourteenth Amendment constitutional right to be free from harm.295/ That right applied equally to both involuntary and so-called "voluntary" residents. Recognizing that Willowbrook residents were "held without the possibility of a meaningful waiver of their right to freedom," Judge Judd ruled that residents were entitled to at least the same living conditions as prisoners, including protection from assaults and correction of conditions violating "basic standards of human decency."296/ To remove immediate hazards to the residents' physical safety and health, the District Court ordered medical, physical therapy, recreation and hygiene measures.

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294. Id. at 27.

295. 357 F. Supp. 752 (E.D. N.Y. 1973).

296. Id. at 765.

Ultimately, the Willowbrook court did not have to reach the right to habilitation issue. That ruling was obviated by a final judgment on consent, a judgment which reflected uncontroverted testimony that Willowbrook was "grossly overcrowded," understaffed and marked by an institutional sub-culture exposing residents to a "custodial orientation" and "non-therapeutic and dehumanizing practices."297/ In the face of that overwhelming evidence and the pressure generated by well-publicized hearings, the parties agreed to phase out the large institution. That remedy also provided for extensive interim habilitation services to prepare residents to exit from Willowbrook and to create a network of community-based services in each of New York City's five boroughs. As Judge Judd stated in an opinion approving the consent decree: "protection from harm requires more extensive relief than this court originally contemplated because harm can result not only from neglect but from conditions which cause regression or which prevent development of an individual's capabilities."298/ Furthermore, the Court pointed out that there is "no bright line" separating the legal rubrics of protection from harm, right to treatment or right to care.299/ Indeed, the scope and comprehensiveness of the Willowbrook remedy exceeded that provided in the Wyatt case. Reduced to its essence, the theory of the case is that supervised movement to community placements offers residents the soundest protection from harm. "Underlying the federal jurisdiction of the Consent Judgment," Judge Bartels recently wrote, "is the protection of the plaintiffs under the

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297. 393 F. Supp. 715 (E.D. 1975).

298. Id. at 718.

299. Id. at 719.

Fourteenth Amendment from harm and gross deterioration."300/ He further stated:

> The release of the mentally ill and retarded from institutions was a response to the demands of justice, medicine and compassion. It must not become a Pyrrhic victory.

Recent Willowbrook orders stress the primacy of movement into the community. Institutions like Willowbrook, geared to long-term institutionalization and demoralized by exposure, cannot and should not be repaired. On June 10, 1977, the court ruled that even the transfer of Willowbrook residents into a new state institution with improved treatment facilities would contravene the Consent Judgment. In reaching this conclusion, the court observed that "normalization is the ultimate goal."300a/ The court found that the benefits in institutional care offered transferred residents were clearly outweighed by the risks. Those transfers were found to create "a risk of loss of present improvement and also of delay in community placement, where the only real improvement in the handicapped and the retarded can be expected."

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300. NYSARC, C.A. No. 72-356/357, Memorandum Decision and Order, (E.D. N.Y. June 10, 1977), (available from Mental Disability Legal Resource Center, No. 1-246).

300a. Id. at 4.

> According to Paragraph V.9 of the (Consent Decree), the primary goal of Willowbrook and the Department is to prepare each resident for life in the community at large. In other words, the goal is to approach normalization. Although it has been asserted that normalization cannot be completely realized since the retarded are different from others, this does not mean that substantial normalization cannot be accomplished.

Testimony further showed: that hundreds of Willowbrook residents had already been placed in good quality homes and community residences; that transitional, intermediate placements hindered the residents' progress; and that institutional congregate care delayed development, caused loss of skills and harmed the handicapped and retarded. The direction of progress, the United States District Court strongly emphasized, pointed toward community-based care:

> The goals of normalization and development of the mentally retarded cannot be met until every effort is made to physically and socially integrate the class members into the mainstream of the community. Their activities should be oriented to community activities and the services delivered to them should be in the same context as community services delivered to others. Such services have been and can be provided by utilization of non-profit agencies as vendors of services for persons coming out of institutions.301/

The case's major innovations include timetables for community placements and a Willowbrook Review Panel to oversee implementing these reforms. The Panel, acting as the "eyes and ears" of the Court, makes field investigations and formal and informal recommendations to the parties regarding problems of compliance. With a full-time staff of program monitors and a seven member panel of leading mental retardation experts, it combines information-gathering and dispute resolution functions.302/ Assisted by consumer and professional advisory boards, the Panel can mobilize a base of political support for its recommendations. Creation of the Panel relieves plaintiffs' attorneys of

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301. *Id.* at 11.

302. 409 F. Supp. 606 (E.D. N.Y. 1976). A similar Panel and a seven-member Consumer Advisory Board were called for in *Horacek* v. *Exon*, *supra* note 260.

considerable burdens of investigating and acting upon day-to-day complaints. Willowbrook Review Panel reports on implementation and community placement plans have also provided data for plaintiffs' motions for contempt orders and further relief.[303] Faced with a trial on those motions, the defendants stipulated more precise timetables for transfer of residents to community settings.[304] Those stipulations also provide for the state contracting with private vendors for habilitation services for residents of certain Willowbrook buildings. Having defined the plaintiff class as all residents of Willowbrook at the time of the suit's filing, the parties, the Panel and the Court can protect former Willowbrook residents from dumping or sub-standard care. While that class definition adds to the litigation's complexity, it ensures that rights to habilitation apply to ex-institutional residents.

Recent mental retardation cases continue this trend toward replacing institutional care with community living arrangements suitable to each plaintiff class member.[305] Halderman v. Pennhurst State School & Hospital [306] posed a frontal challenge to the adequacy of institutional care for mentally retarded persons. Indeed, the court characterized Pennhurst, housing 1250 residents, as typical of large residential state institutions.307/ On the basis of a detailed record, Judge Raymond J. Broderick concluded that many of the residents suffered "physical deterioration and intellectual and behavioral regression during their residency at Pennhurst."308/ By their very nature, institutions such as Pennhurst produce an atmosphere conducive to resident injury and counter-productive to habilitation. Linking habilitation to the requirement of the use of least restrictive settings, the District Court termed Pennhurst "a monumental example of unconstitutionality."309/

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[303] See Willowbrook Review Panel, Report to the Court, Jan. 1 - June 30, 1976, at NYSARC supra.

[304] NYSARC & Parisi v. Carey, No. 72-C-356/357, Stipulation and Order (E.D. N.Y., March 10, 1977) (defendants to create community-based residences and programs for 50 Willowbrook class members a month through October 1977, 75 members through April 1978, and 100 members through April 1979, for a total of 1950 community placements; additional case managers to be hired).

[305] The classes of plaintiffs can be broadly defined to include not only current residents, but ex-residents transferred to other facilities after filing of the suit (NYSARC); or persons on a waiting list for placement, and persons "who, because of the unavailability of alternative services in the community, may be placed" in an institution (Halderman v. Pennhurst 446 F. Supp. 1295, 1300); or persons "served by the mental retardation regions, but not in a residential facility." (Horacek v. Exon, No. 72-C-299, Decree at 2).

[306] 446 F. Supp. 1295 (E.D. Pa. 1977).

The Pennhurst opinion is a rich primer of factual findings and theories of liability. Explicitly rejecting a medical model, it posits mental retardation as "primarily an educational problem and not a disease."310/ Noting a history of misunderstanding and mistreatment of the retarded, the court views mental retardation as a highly suspect classification. Its central findings stress the hazardousness of the Pennhurst environment to residents and the benefits to retarded individuals of transfer from large institutions to small living units in the community. The record reflected consensus that, given appropriate community facilities, "all the residents at Pennhurst, even the most profoundly retarded with multiple handicaps, should be living in the community."311/ Furthermore, all parties accepted the principle of normalization and its application to residential services; namely that the retarded individual is to be treated as much like the non-retarded

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307. Id. at 1309.

308. Id. at 1303.

309. Id. at 1320.

310. Id. at 1298.

311. Id. at 1312.

person as possible. Residency in a large, separate and isolated institution was seen as antithetical to that principle, posing an environment inappropriate for habilitating the retarded.312/ Defendants agreed with these positions, but argued that no legal duty compelled them to transfer Pennhurst residents to education, training and care facilities in the community.

Legal liability was premised on a string of constitutional and statutory violations. Based on substantive due process, the Court held that involuntarily committed retarded persons have a constitutional right to "such habilitation as will afford them a reasonable opportunity to acquire and maintain those life skills necessary to cope as effectively as their capacities permit."313/ Both voluntary and involuntary residents were entitled to "minimally adequate habilitation" removed from Pennhurst, since the Court found voluntarism in connection with Pennhurst admissions to be "an illusory concept."314/ Since residents had no other place to go and all admissions "entail an infringement on fundamental rights and freedoms,"315/the defendants were held under a constitutional duty to explore and provide retarded individuals at Pennhurst with the "least stringent practicable alternatives."316/ The Court found similar violations of a state statutory right to minimally adequate habilitation.317/ On Eighth and Fourteenth Amendment grounds, Judge Broderick held that physical abuse and injuries

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312. Id. at 1311, 1313.

313. Id. at 1317-18. In addition to the Fourteenth Amendment, that right was also predicated on Eighth Amendment and State law grounds (50 P.S. Secs. 4101 et seq) Id. at 1325.

314. Id. at 1318.

315. Id. at 1319.

316. Id. at 1320.

317. Id. at 1322. See 50 P.S. Sec. 4406(b).

constituted a violation of the residents' constitutional right to be free from harm. Following the reasoning of the Willowbrook decision, the Court distinguished Ingraham v. Wright 318/as inapplicable to closed mental institutions.

The Pennhurst court's ground-breaking legal conclusions - rights to non-discriminatory habilitation - are also its most cryptic. On the authority of P.A.R.C. v. Pennsylvania and the "inherently unequal" rationale of Brown v. Board of Education, the District Court found that "the confinement and isolation of the retarded in the institution called Pennhurst is segregation in a facility that clearly is separate and not equal."319/ With little commentary, the Court declared that the same equal protection principles which required retarded children to receive education and training, prohibit the segregation of the retarded in "an isolated institution such as Pennhurst where habilitation does not measure up to minimally adequate standards."320/ On the basis of Section 504 of the Rehabilitation Act of 1973, the Court held that a private right of action is conferred and that Section 504 commands

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318. Id. at 1320-21. In response to defendant's closing argument that the school corporal punishment case, Ingraham v. Wright, 430 U.S. 651 (1977), limited Eighth Amendment protection to persons detained for crimes, the Court strongly interjected:

> You are not going to make the argument to this Court that if Pennhurst is to be continued, its mentally retarded residents can be cruelly treated -- secluded, pushed down stairs -- and that there's no violation of constitutional rights.... Are you saying you can do that with mentally retarded persons, but not with prisoners or juvenile delinquents? I can't buy that.
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> Hearing of October 18, 1977.

319. Id. at 1321-22.

320. Id. at 1322. This rationale for the extension is articulated in Burt, "Beyond The Rights To Habilitation," in Mentally Retarded Citizen, supra, note 148, 425-34.

habilitation be provided in a non-discriminatory manner. Accordingly, the opinion condemned unnecessarily separate and inadequate services as discriminatory and unlawful.321/

The Pennhurst result is sound, even if its legal reasoning is abbreviated. Other courts, in decisions not cited in the opinion, have ordered the closing of custodial or treatment facilities and the provision of alternatives.322/ The Willowbrook and Pennhurst results proceed from a common principle: only in small-scale, integrated settings can mentally retarded persons learn, grow and develop so as to attain their habilitative

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321. Id. at 1323-24. These findings are not elaborated or related to specific parts of the record. Instead, they suggest that mere confinement in a segregated and substandard facility suffices for a Sec. 504 violation.

322. On cases removing residents to alternatives and leading to closing of inhumane institutions, see D.C. Family Welfare Rights Organization v. Thompson, No. 71-1150J, (D.C. Super. Ct., June 18, 1971), reported at 5 Clearinghouse Rev. 419, 463 and discussed extensively at Herr, "Civil Rights, Uncivil Asylums and the Retarded," 43 U. Cin. L. Rev. 679, 745-750, 769 (1974). (Court "clearly empowered to remove (dependent) children, and the class they represent, from a neglectful environment" and order their placement in foster care and other home substitutes) (Slip Op. at 35, 40). Daratsakis v. Smith, No. 76 Civ. 3218 (S.D.N.Y., July 30, 1976), (consent decree fixing closing date for Children's Center, a maximum interim population of 50 children, and extensive monitoring by the Legal Aid Society), reported at 10 Cl. Rev. 392 (1976 No. 18,931).

Martarella v. Kelley, 349 F. Supp. 575 (S.D.N.Y. 1972). (Closing of Zerega Juvenile Detention Center); Morales v. Turman, 383 F. Supp. 53, (E.D. Tex. 1974), remanded for three-judge court, 535 F. 2d 864 (5th Cir. 1976), remanded 430 U.S. 322, 97 S. Ct. 1189 (1977) (three-judge court unnecessary), remanded for further proceedings 562 F. 2d 993 (5th Cir. 1977). (Emphasis on non-institutional setting resulted in the state's closing three facilities and transfer of fourth to Department of Correction; Id. at 569.) One court has threatened to divert inmates to proper penal institutions, noting its power to refuse to incarcerate non-dangerous offenders, to resentence others and to refuse to detain non-dangerous accused persons. These actions, the court acknowledged, would effectively "close down" an adult correctional facility which "continues to operate with apparent disregard for the consitutional rights of the persons incarcerated therein," Barnes v. Government of Virgin Islands, 415 F. Supp. 1218, 1230 (D. V.I. 1976). See also, Rhem v. Malcolm, 371 F. Supp. 594 (S.D.N.Y. 1974).

potentials.323/ The catchment area from which Pennhurst residents are drawn offers community facilities for the education, training and residential care of retarded persons of all ages and degrees of retardation. Thus, the logic of the Pennhurst decision points to a basic principle of equality: to provide other similarly handicapped persons (including the profoundly retarded with multiple handicaps) with residential and other services in less restrictive community settings, while denying segregated Pennhurst residents access to those services contravenes the Equal Protection Clause of the Fourteenth Amendment. Moreover, the defect of confinement at Pennhurst is not merely segregation, but conditions which destroy any reasonable chance of normal opportunities for growth and development. The right to minimally adequate habilitation thus necessarily incorporates a right to services and facilities in the least restrictive, least separate and most community-integrated settings.324/ Whether grounded in substantive due process, equal protection, freedom from harm or statutory non-discrimination rationales, courts can direct transfers to semi-supervised or sheltered small-scale community settings as the most reliable means of protecting residents' rights and preserving their developmental potential.

If Pennhurst must close, few institutions for the mentally retarded are immune from challenge. Although the Court attempts to limit its conclusions to Pennhurst, its logic and its general findings are of national application. Pennhurst can be viewed not as an unspeakable pit, but as a typical large state mental retardation institution, an improving facility staffed by "dedicated" professionals and even certified as meeting Federal Title XIX

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323. See text and notes supra at notes 72-88.

324. Id. at 1319, 1327.

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standards in many of the residents' living areas.325/ Beyond the Pennhurst decision lies a tantalizing question: could an institution be fully certified under Title XIX and still breach the constitutional standard? Under the principles enunciated by Judge Broderick, it seems clear that even the best and the brightest institution defeats the central aims of habilitation.

The remedial order, rather than specifying detailed standards or timetables, opts for a special master and broad injunctive relief. Its principal object is to remove the residents of Pennhurst State School and to provide them and those on its waiting list with suitable community living arrangements and other services in the "least separate, most integrated, least restrictive community settings." The Special Master is to prepare a plan of implementation and a plan for the interim operation of Pennhurst pending "its prompt replacement." Those plans are to address such issues as the quantity and type of required community services; a schedule for individual evaluations, exit and community programs plans; monitoring and correction of conditions at Pennhurst which threaten the life, safety or well-being of any resident until habilitation services in the community can be provided.326/ Novel remedial features include plans for providing "friend-advocates" to protect the rights of each class member, informing those retarded persons and their parents and families of the effect of the Court's decision and providing for consultation with them. By relying so heavily on a planning process, the Court "trades-

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325. Id. at 1302-3.

326. This injunction prohibits new admissions, seclusion, abuse, neglect or mistreatment of residents, improper physical restraints, excessive medication, feeding in the supine position and denying any resident's programmed activities as punishment.

off" specificity for flexibility, arming an executive-type Special Master with supervisory power to fill in the gaps.327/

Replication of successful impact cases poses a major allocation problem. No back-up center exists for this particular purpose. The United States Justice Department has been a major force in bringing cases on the constitutional rights of retarded and other institutionalized persons. Its Special Litigation Section has the resources to provide some consultation to attorneys considering such actions and to become involved as amicus curiae or plaintiff intervenor.328/ A request for the assistance of the Justice Department generally begins by contacting one of the attorneys of the Civil Rights Division, Special Litigation Section, and exchanging documentary and other information. This may be followed by a preliminary investigation of institutional facilities by agents of the FBI or a Section attorney.329/ The Department's internal decision-making processes may, however, take many months, and much local attorney persistence may be required before the United States enters a case.

Legal services programs often have achieved substantial relief without full trial or Justice Department intervention. For tactical or practical reasons, local programs may not need, want or be able to obtain timely Justice

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327. The Special Master, Robert Audette, was formerly in charge of Massachusetts special education programs and had also brought suit as a "next friend" for the lead plaintiff in Saville v. Treadway, 404 F. Supp. (M.D. Tenn. 1974). Unfortunately, he recently resigned for health reasons.

328. Its docket lists some 23 major treatment, civil commitment and sterilization cases. For further discussion of its role and its proposed authorization statute, see Section V. at text and notes 601-604, infra.

329. Interviews with Karen K. Christensen, Justice Department Attorney, in Washington, D.C. (Oct. 3, 1977) and with Louis M. Thrasher (Sept. 1, 1977).

Department assistance. Some programs have received contributions from interested local organizations for litigation costs, or recovered them in post-decree orders.330/ For example, a recent preliminary injunction halts all new admissions of residents to the Plymouth Center for Human Development. It also creates a paid, independent four-person monitoring committee to report violations of residents' rights and provides a system of accountability to protect the 900 residents from abuse, injury or neglect.331/ The threat of seeking the Justice Department's involvement can also provide plaintiffs with greater leverage to negotiate major concessions from recalcitrant defendants. In conjunction with legislative strategies, litigation can result in redirecting mental retardation expenditures to community settings. If substantial evidence of the deficiencies of institutional care were marshalled before certain legislative and regulatory bodies, the public outcry could ultimately produce reforms akin to those now emerging from the courts.332/ Individual cases, presented as test cases and documenting the evidence against

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330. See, e.g., *Welsch* v. *Likens*, 373 F. Supp. 487 (D. Minn. 1978); *Brewster* v. *Dukakis*, C.A. No. 76-4423-F (D. Mass.).

331. *Michigan Ass'n. for Retarded Citizens* v. *Smith*, C.A. No. 870384 (D. Mich., March 3, 1978). The Plymouth Center, built within the last decade, shows that debilitating conditions are also found in new facilities.

332. Forest Haven: Joint Oversight Hearings before the House Subcommittee on Education, Labor and Social Services and the Committee on the District of Columbia, 94th Congress, 2nd Session, H. Rep. 94-19 (April 26, 27 and May 26, 1976); Editorial: "Forest Haven, Forest Haven?," *Washington Star*, April 2, 1977 (House District Comm. calls for abolition and replacement of Forest Haven with group homes). The New York City Council's Public Safety Committee has pledged to use its budgetary powers to close the Spofford Juvenile Detention Center, described as "a dumping ground for emotionally disturbed children," unless the City phases out Spofford and replaces it with smaller centers in each borough. "Council Panel Asks Closing of Spofford," *New York Times*, March 22, 1978 at 37, col. 6. In the District of Columbia, City Council regulations closed the 500-bed Junior Village and replaced it with a community-based childcare system. Herr, *supra* note 322, at 748.

regressive institutional care, could trigger more sweeping inquiries.333/ Impact advocacy is certainly not limited to class actions, and institution-wide relief can be fashioned through selective individual representation.

Settlements of institutional reform suits are not without hazards to residents' interests. The consent decree process may be based on a truncated or wholly inadequate fact-gathering process. The court may not have before it evidence essential to grasping institutional deficiencies or the sub-standard conditions to which residents are exposed. In cases settled without evidentiary findings or the assistance of outside experts, judges may not be aware of the community alternatives to institutions or the costs of institutional reform. Moreover, as in Massachusetts, the price of relief by consent may include the Attorney General's stubborn refusal to acknowledge the constitutional or statutory foundations of the residents' claims to services.334/ This has led to the paradox of a defendant, the Commissioner of Mental Health, openly acknowledging the necessity of class action decrees to relieve unconstitutional conditions in five mental retardation institutions, while his attorney denies that any constitutional violations are involved.

The adequacy of class representation has not yet been candidly confronted in some of these suits. Four years after the filing of one such

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333. In re Zeiler, No. 2035-69 (Penn. C.P., Allegheney Cty, March 31, 1975), reported at 9 Cl. Rev. 140 (1975); 8 Cl. Rev. 573 (1974) (constitutional right to treatment requires county child services and mental retardation programs to cooperate in finding a suitable foster home for a 13-year-old severely retarded girl; finding that institution so grossly overcrowded and understaffed as to make placement detrimental to child). A suitable home was found, and the Court ordered the Department of Welfare to pay per diem costs to foster parents and to provide casework services.

334. See, e.g., M.A.R.C. v. Dukakis, (D. Mass., July 12, 1977) C.A. No. 75-5210 interim consent and the four other cases consolidated before Tauro, J., supra note 258.

suit, the class has yet to be certified.335/ There are private plaintiffs' attorneys who rely on defendants to propose remedies and who seek little or no independent expert assistance in formulating remedial decrees. Even more disturbing is the sharp ideological conflict between those parents' groups who would "clean up" the institutions and those who would ultimately dismantle them.336/ When the "reconstructionists" have their hands on the throttle, an institutional suit can become the vehicle for pouring millions of dollars into brighter and better congregate care facilities. Many admitted their children to institutions decades ago under the influence of pessimistic and uninformed medical advice that the institution was best for the retarded, and they are psychologically threatened by alternative dispositions.337/ Others, properly skeptical of state promises to maintain adequate community care facilities, fear that community placements over time will collapse.338/ Their strategy can result, however, in a self-fulfilling prophecy. Rather than demanding the state's continuing responsibility for follow-up and quality community-based services, the institution-minded would build new cottages on state school grounds, hire masses of untrained employees and renovate even 19th century dormitories. Consent decrees of this type are a disservice to the clients' long-term interests, impede the residents' integration and development and drain resources away from the organization of community-based service

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335. McEvoy v. Stevens, C.A. No. 74-2769 M(T), (D. Mass.).

336. See, e.g., Horacek v. Exon, Civ. 72-C-299, Memorandum Opinion (D. Neb., Oct. 3, 1975).

337. Angelin, "Mark Comes Home," Deficience Mentale Retardation No. 2 (April 1977) at 27. A parent writes: "You also have to deal with the pain of asking 'How could we have allowed his personality to be smothered for so long.'"

338. Telephone interview with Matthew J. Guglielmo, President, Fairview Parents and Friends, Santa Monica, California, Feb. 6, 1978.

networks. The parent of a former resident of a mental retardation institution has expressed the psychological distress of parents who are "determined to see new buildings built to modernize the institution. We sympathize but we know new buildings will stand for another 100 years of differentness like the old ones have."339/

Implementing class action remedies, like implementing new legislation, at best produces partial and incomplete results.340/ Bureaucrats of even moderate imagination can find countless ways of frustrating imprecisely drawn or poorly monitored reforms. Successful class actions require substantial ongoing commitments of the plaintiff attorneys' time, even where remedial standards, monitoring functions, implementation plans, dispute resolution and enforcement mechanisms have been carefully conceived.341/

At some point, courts may decline to exercise a continuing jurisdiction over an institutional reform suit. It becomes vital for plaintiffs' attorneys to consider ways of "internalizing" the relief gained by court order, whether through legislation, departmental regulation or administrative acceptance of the principles embodied in the decree.342/ Class action orders obtained in the teeth of state or staff opposition may prove only partially effective. Advocates for mentally disabled clients need to negotiate resolutions which will minimize staff resistance and alienation and encourage voluntary

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339. Angelin, supra note 337.

340. See, Kirp, Buss and Kuriloff, "Legal Reform of Special Education: Empirical Studies and Procedural Proposals," 62 Cal. L. Rev. 40, 112-113 (1974).

341. Note: "Implementation Problems in Institutional Reform Litigation," 91 Harv. L. Rev. 428, 458 (1977).

342. See, Morris, "Institutionalizing the Rights of Mental Patients: Committing the Legislature," 62 Cal. L. Rev. 957 (1974); Mass. Department of Mental Health, Part 310, "Standards to Promote Client Dignity," (regulations promulgated, Feb. 3, 1978).

compliance. Positive incentives, for example, which reward staff for aiding residents in the exercise of their rights or encourage their movement to more independent living situations should be included in job descriptions. At present, those incentives are lacking, with the result that institutional staff and community program staff often operate in isolation or at cross-purposes from each other. Even with these limitations, class actions have been one of the most effective forms of legal advocacy for the mentally retarded.343/ They have been precursors of legislative appropriations and administrative change344/ and have opened a broad public debate. Yet, the burdens of managing, monitoring and enforcing favorable omnibus class action decrees are substantial and require careful pre-litigation planning. As part of that planning, lawyers should ask: Who will design an implementation plan?345/ What independent experts will review the adequacy of any proposed remedial package?346/ Who will monitor defendants' compliance efforts?347/ What incentives and costs are built into the decree itself that will alter the

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343. Interview with Dean Richard Allen, in Chicago (Aug. 8, 1977). As a veteran researcher in this field, he observed:

> "There are still hundreds of Partlows and worse," and urged that more such actions be brought "to bust patients loose from some terrible places."

344. See, e.g., "Wyatt Standards Found to Be Widely Observed," American Psychiatric News, Oct. 21, 1977, at 1, col. 3.

345. In Halderman, this task has been assigned to the Special Master.

346. In Wyatt, leading staff professionals of the National Association for Retarded Citizens conducted on-site inspections of Partlow and prepared reports.

347. In the Wassaic Developmental Center case, supra note 258, the Sec. 113 Protection and Advocacy System agreed to review the state's Implementation Plan and monitor its implementation.

defendants' behavior in the directions envisaged by the suit?[348] How will consumers and their groups be organized to press for effective implementation? How can the defendants' sensitivity to adverse publicity be turned to the clients' advantage? Litigation planners need to ask how advocacy on the individual level will be provided as an enforcement tool in post-decree phases.

E. Discrete Class Actions

Litigation on behalf of mentally retarded persons need not be synonymous with the omnibus right to habilitation class action. Legal services lawyers, meeting particular client needs or lacking resources to conduct massive litigation on the scale of Wyatt or Welsch, have pursued more narrowly drawn claims.[349] Moreover, once litigation has begun, attorneys may, through negotiation or complaint amendment, be able to obtain additional relief.[350] Suits framed around one or two urgent issues, in addition to being more manageable and yielding faster results, can focus judicial and administrative attention on what plaintiffs regard as matters of highest priority. Thus, for example, in institutions with units of sharply varying quality, a constitutional right to treatment suit could be successfully maintained for the inmates of buildings with the most intolerable conditions.351/ Children352/ and wards of the state353/ may acutely need class action representation before and after institutional admission. Class action relief can be obtained for special groups of retarded inmates, such as persons whose retardation is accompanied by emotional disorders,354/ mentally retarded offenders355/

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[348] The costs of commitment, for example, can be dramatically raised by due process safeguards and the right to treatment. Ingber, "Procedure, Ceremony and Rhetoric: The Minimization of Ideological Conflict in Deviance Control," 56 Boston U.L. Rev. 266, 319 (1977):

> "A simple means of influencing behavior is to make such behavior so difficult or costly as to render it undesirable in comparison with alternative allocations of time and resources."

[349] Some legal services attorneys hesitate entering the mental retardation field because they equate legal advocacy for mentally handicapped clients with these omnibus suits (See Section V, on priorities, infra).

[350] See, e.g., Morales, supra note 322, Wyatt.

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351. *Vanderzeil* v. *Hudspeth*, C.A. No. J76-262(R) (S.D. Miss., Feb. 11, 1977) 1 MDLR 450 (May-June, 1977). (Class of some 80 women inmates of Building 49 at Mississippi State Hospital at Whitfield have constitutional right to treatment.) *Crouse* v. *Murray*, No. S-75-191 (N.D. Ind. filed Nov. 17, 1975), reported at 9 Cl. Rev. 657 (1976) #16,952. (*Wyatt* standards sought for civilly committed patients confined to hospital's maximum security division).

352. See, e.g., *Bartley* v. *Kremens*, 402 F. Supp. 1039 (E.D. Pa. 1975); *Heryford* v. *Parker*, 396 F. 2d. 393 (10th Cir. 1968); *In re Roger S.*, 19 Cal. 3d 921 (Cal. Sup., 1977) (minors 14 or older admitted "voluntarily" by parents or guardian entitled to due process hearing).

353. *In re Lee*, No. 68J(D)1362 (Ill. Cir. Ct., Cook Cty, March 5, 1975) (State required to provide services and habilitation plans for mentally retarded and other handicapped wards, with monitoring by independent utilization review comm.) reported at 9 Cl. Rev. 58 (1975), (#6335).

354. *Ohio Ass'n. for Retarded Citizens* v. *Moritz*, C2-76-398 (S.D. Ohio, April 19, 1977) (consent order on preliminary injunction requires state to evaluate 300 retarded institutional residents who need mental health services, to establish six special units providing appropriate treatment, to arrange on-site inspection of those units and to plan for community-based services for residents discharged from state facilities) *Nathan* v. *Levitt*, No. 74-CH 4080 (Ill. Cir. Ct., Cook Cty., March 26, 1975), rep. at 9 Cl. Rev. 58 (1975), (#13,104), (evaluation and placement procedures to secure appropriate treatment).

355. See *Jackson* v. *Indiana*, 406 U.S. 715 (1972); *Pate* v. *Parham*, No. 75-46-MAC (M.D. Ga., filed March 19, 1975), reported at 9 Cl. Rev. 212 (1975) #15,730. *Pugh* v. *Locke*, 406 F. Supp. 318 (M.D. Ala. 1976). (State officials to identify disturbed or mentally retarded inmates in Alabama prison system and transfer them to facilities designed for such persons). See also, *Davis* v. *Watkins* 384 F. Supp. 1196 (N.D. Ohio 1974), *Newman* v. *Alabama* 349 F. Supp. 278 (M.D. Ala. 1972), aff'd 503 F. 2d 1320 (5th Cir. 1974) *cert. den.* 421 U.S. 948 (1975), Robbins & Buser, "Punitive Conditions of Prison Confinement: an Analysis of *Pugh* v. *Locke* and Federal Court Supervision of State Penal Administration Under the Eight Amendment," 29 *Stanford Law Review* 893 (1977); See generally M. Santamour and B. West, *The Mentally Retarded Offender and Corrections* (1977) (GPO No. 027-000-00528-4), (23,700 or 9.5% of total prison population tested as retarded).

or mentally retarded juvenile delinquents.356/ Those cases point out the need for special and more appropriate facilities and services for mentally disabled persons marooned between the jurisdictions of two state agencies.357/

Deinstitutionalization should be a prime focus of impact actions for the mentally retarded. Lawyers in the earlier cases have sought 358/ or obtained post-decree orders to speed the movement of residents to appropriate community care facilities.359/ Other Federal class actions, although addressing the full gamut of institutional issues, lay major stress on community placement objectives.360/ Several recent cases rest almost exclusively on claims to

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356. See, e.g., Doe v. Henderson, No. A-7980-1 (Tenn. Chan. Ct., Davison Cty., filed Sept. 10, 1976); Morales v. Turman, 383 F. Supp. 53 (E.D. Tex. 1974). See generally, Wald & Schwartz, "Trying a Juvenile Right to Treatment Case," 12 Am. Civ. L. Rev. 125 (1974).

357. On conflicts between the Federal Indian Health Service and state mental authorities in provision of mental health care, see White v. Weinberger, (D.S.D. filed April 16, 1976) 10 Cl. Rev. 142 #18,122 (TRO preventing state from refusing to treat an Indian).

358. Wyatt v. Hardin, C.A. No. 3195-N, (M.D. Ala., April 12, 1978). (discovery in Alabama's retardation facilities reopened and hearing for further relief scheduled).

359. NYSARC v. Carey, Stipulations and Order of March 10, 1977, supra note 304.

360. See, e.g., Sidles v. Delaney, No. C75-300A (N.D. Ohio, April 26, 1976). (Consent order requires, inter alia, comprehensive master plan to develop community facilities and programs for all mentally retarded class members transferred from Apple Creek State Institute; assignment of case manager to each resident transferred to community or another facility, whose duty it is to ensure follow-up and implementation of individual habilitation plans).

less restrictive treatment or habilitation alternatives.361 That emphasis recognizes the impracticality of states simultaneously upgrading institutional facilities and developing community-based alternatives. Creating new jobs within the institution may add new economic sources of resistance to community care without appreciably improving residents' care.362/

Other litigation has restricted new admissions and forced public agencies to establish alternatives. Bartley-type actions have sometimes had this result.363/ "Right to treatment" suits have required freezes in admissions to obsolescent state facilities.364/ Adding further due process safeguards to the admissions process may also deter inappropriate admissions. Judicial and legislative restrictions on guardian-initiated admissions can

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361. See Kentucky Assoc. for Retarded Citizens v. Conn, No. C-77-0048P (W.D. Ky., filed June 2, 1977) (plaintiffs represented by Legal Aid Society of Louisville). Doe v. Yuen, Civ. No. 77-0059 (D. Hawaii, filed Feb. 12, 1977), (Legal Aid Society of Hawaii represents complainant class of involuntarily committed persons at Hawaii State Hospital seeking less restrictive alternatives and injunctions prohibiting receipt of Federal funds under P.L. 94-63 until appropriate alternatives to hospitalization are provided); Barbara C. v. Moritz, C2-77-887 (D. Ohio, filed Nov. 17, 1977) (Ohio Legal Rights Service, acting as best friend of named plaintiffs and for class of over 2,000 residents of Orient State Institute seeks comprehensive evaluations, individualized adult education, vocational and appropriate residential services). Dixon v. Weinberger, 405 F. Supp. 974 (D.D.C. 1975) (Joint duty of Federal and District officials to provide plaintiff class with a right to suitable treatment and care under the least restrictive conditions).

362. Grant & Moores, "Residents Characteristics and Staff Behavior in Hospitals for Mentally Retarded Adults," 82 American J. of Mental Deficiency 259, 263 (1977) ("A major implication of this study is that the investment of more manpower in institutional programs appears not to affect appreciably the adaptive behavior levels of retarded adults").

363. Saville v. Treadway, 404 F. Supp. 430 (M.D. Tenn. 1974).

364. Such action was taken in the Willowbrook, Wyatt and Pennhurst cases.

spare their wards unnecessary institutional stays.365/ Advocates have also begun to extend due process safeguards to retarded persons facing group home admission 366/ or recall to institutions under conditional discharge procedures.367/ In many states, cases challenging exclusionary zoning have permitted the opening of group homes for retarded or other disabled persons in residential neighborhoods.368/ The wisdom of communty-based habilitation is

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365. See In re the Limited Guardianship of Shelia Anderson, No. 5074-1 (Wash. Ct. App., May 31, 1977) (1 MDLR 451, May 1977), (non-consenting ward may not be placed in residential mental hospital by her limited guardian). Mass. Sess. Laws, "An Act further regulating the powers of guardians to admit or commit wards to mental health or retardation facilities without the consent of the ward," Ch. 567, Acts of 1977.

366. See Opinion of the Maryland Attorney General, Nov. 7, 1975, 1 MDLR 15 (July 1976). (In view of stigma that may attach to residents of group homes for the retarded, a person of legal age to be admitted to, or transferred from a public institution to a group home must be afforded the same notice and opportunity for a hearing as if admitted to an institution for the mentally retarded).

367. Frederick v. Mulcahy, C.A. 76-257 (D. Vermont, filed Dec. 16, 1976 (consent order requires due process hearing for former residents at Brandon Training School facing revocation of conditional discharge status, and periodic review of status). Accord: Meisel v. Kremens, 405 F. Supp. 1253 (E.D. Pa. 1975). (Summary revocation of patient's leave of absence violates 14th Amendment due process of law).

368. Little Neck Community Association v. Working Organization for Retarded Children, 52 A.D. 2d 90 (NY Sup. Ct., App. Div. 2d Dept. 1976) Harbor Schools Inc. v. Board of Appeals of Haverhill, E.75-598 and E.75-599 (Mass. Appeals Court, 1977). (Affirming lower court judgments that community residence for the education of emotionally disturbed children serves a public educational purpose and is thus exempted from the use restrictions of the Haverhill zoning ordinance.) Michigan Ass'n. for Retarded Citizens v. Village of Romeo, No. 670769 (E.D. Mich. August 8, 1977) (eight developmentally disabled persons living with foster parents in a foster home deemed a family). Group House of Port Washington, Inc. v. Board of Zoning, 82 Misc. 2d 634, 370 N.Y.S. 2d 433 (1976) (local ordinance barring group home, void as contrary to state policy). See also, Kline v. NY State Department of Mental Hygiene, No. 76-C-661 (E.D. N.Y. 1976). (In a free society, citizens do not have the right to demand that persons who are different from themselves be forced to reside somewhere else.) Zarek v. Attleboro Area Human Services, Inc., No. 2450 (Mass. Super. Ct., Bristol Cty., June 11, 1976), reported at 9 Cl. Rev. 657, 10 Cl. Rev. 231 (1976) (community residence for former mental patients under DMH's Normalization Program is educational, not medical facility, thus exempting group residence from local zoning

reaffirmed by a pattern of consent decrees, settlement negotiations[369] and even the appearance of lawyers for institutions urging the diversion of prospective residents to less restrictive settings.[370]

Another species of impact litigation focuses on recurring harm to institutionalized clients. Michigan class actions have begun to probe chronic problems of resident abuse and the failure of state protective services to reach those within mental retardation facilities.[371] Other actions have safeguarded mentally retarded persons subject to sterilization without their consent.[372] Cases probing the limits of medical treatment for mental inmates unwilling or unable to grant consent have exposed a Pandora's box of problems

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368. Cont'd.
ordinance); See also Bell v. Pierce County Board of Commissioners, No. 231992 (Wash. Super. Ct., Pierce Cty., filed Jan. 1975), (institutionalized mentally retarded persons seek judicial review of zoning decision rejecting special use permit for group homes).

[369] Telephone interview with Steven Schwartz, July 19, 1978. (State and representatives of Northampton State Hospital residents meeting regularly and making progress in resolving amicably issues raised in Brewster v. Dukakis, supra.)

[370] See, e.g., In the Matter of Anna H. Kelsey, Mental Health No. 86-26 (Fiduciary Div., D.C. Super. Ct., May 18, 1977), 2 MDLR 15 (July 1977) (St. Elizabeths Hospital has standing to raise conservator's failure to fund ward's community placement, and court ordered conservator to spend $200 a month for a trial 2-month foster home placement).

[371] Karolak v. Dempsey, C.A. No. 77-18 (Mich. Ct. of App., filed Jan. 4, 1977); (writ of mandamus sought against Dept. of Social Services and its Children's Protective Services to develop rules for protection of retarded residents at the 800-bed Plymouth Center for Human Development.).

[372] Wyatt v. Aderholt, 368 F. Supp. 1382 (M.D. Ala. 1973); In re Lambert, No. 61156 (Tenn. Prob. Ct., Davidson Cty., March 1, 1976), 1 MDLR 123 (Sept. 1976) (Probate court without jurisdiction to appoint mother as conservator for mentally disabled minor for purposes of consenting to hysterectomy). But see, North Carolina Assoc. for Retarded Citizens and United States v. North Carolina, 420 F. Supp. 451, 454, 459 (E.D. N.C. 1976). See generally Burgdorf and Burgdorf, "The Wicked Witch is Almost Dead, Buck v. Bell and The Sterilization of Handicapped Persons," 50 Temple L.Q. 995 (1977).

relating to misuse of psychotropic drugs and inadequate medical care for the institutionalized.373/ Federal decisions since the Supreme Court's Ingraham holding374/ have made clear the vitality of Eighth Amendment claims for residents and patients of mental facilities.375/ Given patterns of widespread violence in state mental institutions, with residents' injuries inflicted both by staff and fellow inmates, there is every likelihood of an increasing number of "protection from harm" suits filed against lax administrations and not merely low-level employees.376/

Important educational issues remain untested in institutional contexts. State assurances of education for all handicapped children are more often paper plans than real directives to authorities responsible for institutiona-

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373. See, e.g., Rogers v. Macht, C.A. No. 75-1610-T (D. Mass., filed April 30, 1975); Superintendent of Belchertown State School v. Saikewicz, Mass. Adv. Sheets 2461 (Mass. Sup. Jud. Ct., Nov. 28, 1977); Plotkin, "Limiting the Therapeutic Orgy: Mental Patients' Right to Refuse Treatment," 72 Nw. L. Rev. 461 (1977).

374. Ingraham v. Wright, 430 U.S. 651 (1976) (note 37 of that Opinion expressly declined to reach question of scope of Eighth Amendment protections for mental or juvenile detainees).

375. Halderman v. Pennhurst, 446 F. Supp. 1295, 1320-21 (E.D. Pa. 1977); Romeo v. Youngberg, C.A. No. 76-3429 (E.D. Pa. June 6, 1977) (denying motion to dismiss complaint of a profoundly retarded Pennhurst resident alleging injuries from 63 assaults within the institution). See also, Bowring v. Godwin, 551 F. 2d 44 (4th Cir. 1977) (denial to prisoner of psychological diagnosis and treatment may constitute an Eighth Amendment violation).

376. Mental Health Information Service, Report on the Adequacy of the Current Grievance and Disciplinary Procedures of the Department of Mental Hygiene in Safeguarding the Rights of Patients Involved in Incidents of Abuse and Mistreatment (Submitted to the Legislature of the State of New York Pursuant to the Direction of Chap. 334 of the Laws of New York, 1976.) (DMH system for handling patient abuse complaints "reveals serious flaws requiring immediate remedy if the right of patients to humane treatment is to be protected adequately," (at 7), failure of DMH or patient complainant to have effective legal assistance in proceedings against employees suspected of patient abuse.) See Romeo, supra note 375. See also, Donaldson v. O'Connor, TCA 1693 (N.D. Fla. Feb. 4, 1977) ($20,000 settlement approved).

lized children.377/ State laws reforming the special education field, to be effective, need some enforcement through the court.378/ Children and young persons in institutions rarely receive the benefits of education in the least restrictive environment.379/ The barriers which limit these children's access to school placement in the community, or to any schooling at all should be the subject of intense judicial scrutiny. Compensatory education should be required for those beyond the ages now legally mandated, particularly for handicapped adults who were previously deprived of their right to attend public schools.380/ Vocational education and adult basic education programs often exclude the more handicapped, an entrenched practice vulnerable to litigative challenge.381/ Education and ancillary physical, speech or medical

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377. Mattie T. v. Holliday, No. DC75-31-S (M.D. Miss., filed July 20, 1977); Harris v. Kean, No. 76/323 (D.V.I. Sept. 15, 1976), (Section 504 29 USC 794) violation alleged; state & Federal defendants ordered to devise and prepare plans for education programs meeting requirements of St. Croix population).

378. See, e.g., Allen v. McDonough, C.A. No. 14948 (Mass. Super. Ct. Suffolk Cty., Aug. 8, 1977).

379. For that Federal mandate, see 20 U.S.C. Sec. 1412(5), 45 C.F.R. Sec. 121a, 550, 551-556 (1977). See e.g., Morgan v. Sprout, 432 F. Supp. 1130, 1150-53 (S.D. Miss. 1977). Massachusetts Ass'n. for Retarded Citizens v. Dukakis C.A. No. 75-5024-C, (D. Mass. July 29, 1976), (interlocutory order to identify all school-aged children in institutions not receiving full education programs and resources for completing case evaluations and implementing special education programs); New Jersey Ass'n. for Retarded Citizens v. Klein (N.J. Ch. Div., Super. Ct., Trenton, filed 1977). State of New Mexico ex rel Stromberg v. State Hospitals and Institutions Dept., No. SF77-971 (New Mexico Dist. Ct., Santa Fe Cty., Jan. 3, 1978) (Settlement Agreement).

380. In Allen v. McDonough, supra note 378, Boston School defendants were ordered to provide compensatory special education services, including extra tutoring and special services beyond age 22, for plaintiffs whose special education had been delayed.

381. Davis v. Wynne, No. CV-176-44 (S.D. Ga. 1976) reported at 10 Cl. Rev. 210, 626 (1976) (settlement of Sec. 504 suit for learning disabled high school student expelled as a result of his handicap by providing referral and fees for technical school) #18,404. Massachusetts Advocacy Center, Equal Opportunity Denied: Vocational Education in Massachusetts (1976). Barbara C. v. Moritz, supra note 361.

therapies are often rationed in ways which leave institutionalized or more severely handicapped persons at the end of the queue.

F. Individual Representation

Frontier issues of law and policy will only surface through increased legal services at a grass roots level. The issues for individuals who are retarded, or are perceived as retarded, are as varied as those affecting any other group of poor persons - governmental benefits, housing, employment and family problems, to name but a few. To these must be added the special problems - and possibilities - which accompany disability and prejudice: civil commitment, guardianship, special education, discrimination, SSI benefits and fiduciary relationships. Institutionalization adds other layers of concern and difficulty: aversive behavior techniques, forced or inappropriate medication, misuse or mismanagement of residents' funds, abuse and terror. For the retarded, remarkably little representation occurs at any of these levels of concern.

The lower courts and administrative tribunals can compel real gains for individual clients. Suits for individual relief can also be framed to expose systematic breakdowns in the implementation of statutory rights. In Massachusetts and Ohio, state courts have recently ordered community residential placements for institutionalized retarded persons denied the "least restrictive environment."382/ In Pennsylvania, state court decisions have required local and state officials to meet statutory duties by providing retarded children and adults with community rather than institutional

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382. In the Matter of Deborah P., No. 76-26504 (Ohio Common Pleas Ct., Prob. Div., Pickway Cty., April 6, 1977). In re Stanley P., No. 14934 (Mass. Dist. Ct., Dorchester, May 11, 1978).

services.[383] Before a California Superior Court, public defenders have strenuously urged the transfer of a mildly handicapped 13-year-old boy out of a state retardation institution to foster care even over parental objection.[384] In New York, a long line of cases have questioned institutional care[385] and have ordered residential schooling for young people who might otherwise be shunted to custodial institutions.[386] All this activity bears the mark of a common principle: that services intended for the benefit of mentally retarded persons actually benefit them, and not merely suit the convenience of society or others.

Discrimination against the mentally handicapped poses other frontier legal issues. Retarded or other developmentally disabled workers may suffer from discriminatory employment practices and denial of fair representation from the unions to which they belong.[387] Section 503 of the Rehabilitation Act provides a remedy for such employment discrimination engaged in by those with Federal contracts over $2,500,388/ while Section 504 prohibits employment and other discrimination against handicapped persons in any Federally funded program or activity.389/ Numerous courts have held that these provisions give rise to a private cause of action.390/ It may be argued that lack of a prompt and effective Federal administrative remedy permits prompt judicial recourse. Advocates for the disabled have substantial community education, outreach and counseling tasks before these Federal and state anti-discrimination laws will have bite.391

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[383] *In re Joyce Z.*, a minor child, No. 2035-69 (Pa. Common Pleas, Allegheney Cty., filed March 31, 1975). *In re Zeiler*, *supra* note 333.

[384] *Adamson* v. *Lackner*, Civ. No. M243830 (Cal. Super. Ct., L.A. Cty., filed Nov. 8, 1977) (writ of habeas corpus for child confined from age 4 through age 13 contrary to individual program plan calling for community-based placement).

[385] See, e.g., *Renelli* v. *Dept. of Mental Hygiene*, 73 Misc. 2d, 261, 340 N.Y. F.2d 498 (Sup. Ct. 1973); *Dept. of Mental Hygiene* v. *Schneps*, 480 N.Y.S. 2d 980, 983 (A.D., 1st Dept., 1978) (parents of former Willowbrook resident absolved of statutory obligation to pay fees for their daughter's less than minimally adequate care and "grossly inadequate maintenance").

[386] See, e.g., *Usen* v. *Sipprell*, 71 Misc. 2d 633, 336 N.Y.S. 2d 848 (Sup. Ct. Erie Co., 1972) rev'd. and transferred to Family Court, 41 A.D. 251, 342 N.Y.S. 2d 599 (App. Div., 4th Dept. 1973); *In re Graham S.*, 356 N.Y.S. 2d 768 (Fam. Ct., Kings Co. 1974); *In re Downey*, 340 N.Y.S. 2d 687, 690 (Fam. Ct. N.Y. City 1973); *In re Held*, 323 N.Y.S. 2d 302 (Fam. Ct., Westchester Cty. 1971).

[387] See, e.g., *Smith* v. *United States Postal Service*, C.A. No. 76-2452-S (D. Mass., filed June 26, 1976), MDLR 204-5 (Nov. 1976); *Drennon* v. *Philadelphia General Hospital*, 428 F. Supp. 809 (E.D. Pa. 1977).

The virtual absence of legal assistance to individuals in institutions, residential facilities or day care centers threatens to nullify the rights of the retarded. Court decisions have curtailed state invasions of residents'

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388. 29 U.S.C. Sec. 793; for cases decided administratively, see 2 Mental Disability L. Reporter 19 (1977).

389. 29 U.S.C. Sec. 794. See Wolff, "Protecting the Disabled Minority: Rights and Remedies Under Section 503 and 504 of The Rehabilitation Act of 1973," 22 St. Louis U.L.J. 25 (1978). Comment: "Toward Equal Rights for Handicapped Individuals: Judicial Enforcement of Section 504 of the Rehabilitation Act of 1973," 38 Ohio State L.J. 677 (1977).

390. Lloyd v. Regional Transportation Authority, 548 F. 2d 1277 (7th Cir. 1977); Halderman v. Pennhurst, 446 F. Supp., 1295, 1323 (E.D. Pa. 1977); Barnes v. Converse College, 436 F. Supp. 635 (D.S.C. 1977); Gurmankin v. Costanzo, 411 F. Supp. 982 (E.D. Pa. 1976), aff'd. 556 F.2d 184 (3rd Cir. 1977). See generally, Note: "Enforcing Section 504 Regulations: The Need for a Private Cause of Action to Remedy Discrimination Against the Handicapped," 27 Cath. U. L. Rev. 345 (1978).

391. For consumer handbooks on these anti-discrimination provisions, see Advocates for the Developmentally Disabled, et. al., Section 504 Handbook: The HEW Regulations (June 1977, available from the Public Interest Law Center of Philadelphia); Children's Defense Fund, 94-142 and 504; Numbers that Add Up to Educational Rights for Handicapped Children (1978). For a survey of state statutes, see Comment: "Access to Buildings and Equal Employment Opportunity for the Disabled," 50 Temple L. Q. 1067 (1977).

funds,392/ but, without advocates to counsel residents in the use of money, those funds accumulate to no advantage.393/ New education laws guarantee appropriate schooling for the handicapped, but those entitlements go unclaimed because of state and Federal failure to implement the requirements that surrogates be appointed to aid institutionalized or other school age persons without familial support.394/ Under Medicaid regulations, residents are to receive notification and annual explanation of their rights, but institutions make little or no effort to obtain counsel or counsel substitutes to provide residents with an independent and accurate notification. Advocates are also unavailable to assist residents in the periodic reviews which can fix a resident's fate for a twelve month period. On paper, Human Rights Committees, periodic review teams and other decision-makers have wide powers to protect residents' rights. The absence of attorneys and other residents' advocates, however, leaves those powers unexplored, those rights unenforced.

Attorneys have scarcely begun to litigate these human rights, let alone define these human obligations.395/ Breakthroughs will surely require a quantum increase in individual representation to ensure coverage of vulnerable

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392. Vecchione v. Wohlgemuth, 377 F. Supp. 1361 (E.D. Pa. 1974), 426 F. Supp. 1297 (E.D. Pa. 1976, aff'd 558 F.2d 150 (3rd Cir. 1977) ($9.1 million ordered paid back to residents). See e.g., Albrecht v. Tepper, No. H-263 (D. Conn. Feb. 10, 1977). (Unconstitutional appointment of Department of Finance and Control as conservator for persons in state mental disability institutions).

393. See In re Kelsey, supra note 370. (Fiduciary ordered to expend funds on foster care for resident of state mental hospital.)

394. On the assignment of a surrogate, a child's advocate, when the parent or guardian is unknown, unavailable or the child is a ward of the state, see 20 U.S.C. Sec. 1415(b)(1)(8); 45 C.F.R. Sec. 121a 514.

395. For exceptions, see In re Hospitalization of C.B., (No. AM-774-75) (N.J. Super. Ct., Mercer Cty., App. Div., filed Aug. 2, 1976), (treatment plan reviewed regarding electro-prod used to reduce self-injurious behavior of autistic child), reported in 10 Clearinghouse Rev. 471 (1976) (#19,121). Price v. Sheppard, 307 Minn. Rep. 250, 239 N.W. 2d 905 (Minn. Sup. Ct., Feb. 20, 1976) (electroshock treatments not

populations. Newer advocacy organizations for the developmentally disabled correctly shun a law reform-service case distinction and conceive of each case as having some potential for system-wide impact. The Vermont Developmental Disabilities Advocacy Project, devoting two-thirds of its energies to individual representation, has won that state's first special education placement hearing under P.L. 94-142,396/ obtained procedural safeguards in a Federal class action for group home residents threatened with institutional recommital 397/ and secured passage of legislative reforms.398/ The Ohio Legal Rights Service has complemented their day-to-day advocacy efforts for individual residents with major class action institutional suits.399/ Minnesota Legal Services attorneys have managed a singular feat: while its Executive Director successfully sued the state for millions of dollars of relief for residents of mental retardation institutions, other program attorneys obtained State Developmental Disabilities Council grants for one of

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395. Cont'd.
cruel and unusual punishment; however, for incompetent or non-consenting patient, procedures required include appointment of guardian ad litem, probate court adversary proceeding before probate or committing court as to the necessity and reasonableness of prescribed treatment).

396. In re Peter L., reported in K. Winslow, "Child in Program Parent, Not City, Want for Him," Burlington Times Argus, Jan. 13, 1978.

397. Frederick v. Mulcahy, C.A. 76-257 (D. Vt., filed Dec. 16, 1976).

398. See text and notes at 408, infra.

399. Areas of concentration for Service attorneys included civil commitment, development of family homes and other community residential facilities, educational services, employment rights, nursing home "care" and children's services for developmentally disabled people. Interview with Douglas Rogers, Director, Ohio Legal Rights Service in Columbus, Ohio (Dec. 2, 1977).

the country's first specialist legal advocacy projects.400/ State funded advocates in New Jersey and New York have also used impact litigation to secure treatment rights in the less restrictive settings for individual retarded clients.401/

G. Legislative and Regulatory Reform

The monumental failure of institutions for the mentally retarded stands as an open invitation to legislative and regulatory action. It is not for the judiciary alone to vindicate constitutional rights or to foster a system of community-based care preserving retarded persons from well-recognized harms. In many states lawyers have pressed for more thoroughgoing reforms for mentally disabled clients through legislative or administrative means. Because judicial resolutions are visible, sometimes dramatic, and always lawyer-centered, attorneys have not done enough to pursue the claims of retarded clients before the coordinate branches of government. Health planning legislation, for example, provides a method for opposing the counterproductive renovation or new construction of mental disability care

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400. For some project cases, see *Anderson* v. *Shoreview City*, No. 401572 (Minn. Dist. Ct. Ramsey Cty., July 1975) reported at 9 Cl. Rev. 278 (1975) ¶15,941 (group homes for the mentally retarded in a single family residential zone under special use permit upheld: "our Legislature has established as the policy of this State that mentally retarded and physically handicapped persons should not be excluded by municipal zoning ordinances from the benefits of normal residential surroundings.") *Insurers Action Council* v. *Heaton*, 423 F. Supp. 921 (D. Minn. 1976).

401. *In re C.S.*, No. NHCC 11-75 (N.J. Law Div., Hunterton Cty., April 18, 1977 (right to adequate habilitative care); *Caroll* v. *Cobb*, 139 N.J. Super. 439 (App. Div. 1976) (right to vote). The New Jersey Department of the Public Advocate, through its Division of Mental Health Advocacy, has litigated a wide range of commitment, guardianship and least restrictive treatment cases. Letters from Michael L. Perlin, Division Director, to Stanley Herr, April 1, 1977. See also *Kresselbrenner* v. *Anonymous*, 38 N.Y. 2d 161, 350 N.Y.S. 2d 889 (1973) (least restrictive alternative case brought by MHIS attorneys).

facilities through a "certificate of need" process.402/ Advocates for the mentally retarded have appeared in only a few such hearings, and hence, by default, a potential lever for deinstitutionalization remains unexplored.

Laws in many states reflect an obsolescent view of retarded persons as requiring coercive measures and institution-centered care.403/ Indeed, serious constitutional questions are raised by the commitment of retarded persons on the basis that they pose a danger to society.404/ Mentally retarded persons in Mississippi have been liable to civil commitment for being a "menace" to the happiness or safety of themselves or others.405/ Inappropriate terminology and concepts abound, with references to "idiots," "feeble-minded persons," and "mental deficients."406/ Guardianship laws still

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402. National Health Planning and Resources Development Act, 42 U.S.C. Secs. 300K et. seq. (1974); Mass. Gen. Law Ch. 111 Sec. 25-b.5. See generally, Schneider & Wing, "National Health Planning and Resources Development Act of 1974," 9 Cl. Rev. 683 (1976); Note: "The National Health Planning & Resources Development Act and State Action: A Reappraisal of the Role of Private Health Care Institutions," 57 Boston U. L. Rev. 511 (1977). Kentucky Ass'n. for Retarded Citizens v. Conn., No. C-77-0048 (W.D. Ky. filed June 2, 1977).

403. New commitment laws have markedly curtailed state authority to commit mentally retarded persons. See, e.g., Kentucky Mental Retardation Hospitalization Act, Ky. Rev. Stat. Sec. 202 B.040 (Bobbs-Merrill 1977). (No involuntary admission unless (a) immediate danger to self or others as a result of mental retardation, (b) treatment reasonably expected to benefit the individual is available in the facility, and (c) admission is the least restrictive alternative mode of treatment.

404. Halderman v. Pennhurst State School, 466 F. Supp. 1295 (E.D. Pa. 1977); Institutionalized Juveniles v. Secretary of Public Welfare, No. 72-2272, (E.D. Pa. June 14, 1978) dissenting slip. op. at 5; Herr, "Rights Into Action," 26 Cath. U. L. Rev. 203,308 (1977); Dybwad & Herr, "Unnecessary Coercion: An End to Involuntary Civil Commitment of Retarded Persons," 31 Stanford L. Rev. (in press 1979).

405. Miss. Code Ann. Sec. 41-19-1-1 (1973).

406. See, e.g., Ark. Stat. Ann. Sec. 59-1101 (1971) ("child or children means mentally deficient persons without regard to chronological age"). For legislation removing the words idiot, lunatic, imbecile and feeble-minded from state statutes, see Kentucky Rev. Stat., Ch. 92, I. 1978 Advance Legislative Serv. 123 (Bobbs-Merrill 1978).

provide only limited due process safeguards and impose sweeping restrictions without regard to less drastic alternatives.407/ In most states, major legislative law reform in the mental retardation field is overdue, and attorneys will need to participate in the wholesale overhaul of the statutes regulating institutional care and its alternatives. In Vermont, for example, legal services attorneys have drafted and won passage of legislation to regulate protective services, provide judicial reviews for all State Training School residents and facilitate access to education for institutionalized persons.408/ Such legislative advocacy offers a means for organizing and unifying consumer interests in a viable coalition, a badly needed political force during the new law's implementation stages.

Changes in public policy, Federal law and scientific findings have been so rapid that no state can regard its mental disability laws as wholly updated. Legislative reforms are often incomplete, even in states which pride

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407. ABA Legislative Project for Developmentally Disabled Persons, "A Review of State Guardianship Legislation: Introduction," (1977).

408. Neil H. Mickenberg, Summary of D.D. Legislation Enacted in Vermont During the 1978 Legislative Session (unpublished memorandum, April 7, 1978). These laws include:

H.652 - (Education of State Wards and Handicapped Children in Group Homes and State Institutions)

H.698 - (Zoning for Group Homes)

H.579 - (Protective Services for Retarded Adults)

S.170 - (Community Services)

H.231 - (Automatic Judicial Review of Legal Status and Habilitative Progress of Training School Residents).

themselves on their progressive social welfare orientations.409/ In 1976, California passed comprehensive laws to strengthen the rights of developmentally disabled persons.410/ Legislative specialists are, however, troubled by a lack of oversight and advocacy provisions to realize those rights for the intended beneficiaries.411/ Advocates in Minnesota were successful in fighting zoning exclusions against group homes through legislation, but now are searching for a more flexible and generous funding stream to develop those homes.412/ A set of legislative proposals has been advanced for the mentally ill,413/ and another set is being drafted for the developmentally disabled.414/ These model statutes and commentaries may prove starting points for local advocacy efforts. New statutes and regulations can provide the fiscal incentives and civil rights protections to solidify the gains of case law.

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409. Minnesota Mental Retardation Protection Act, Minn. Stat. Ann. Section 252A.01 (1976 Supp.) (full due process hearing, including appointment of counsel prior to civil commitment, prior to appointment of guardian or conservator, or at any time ward or conservatee wishes to challenge legal status or fiduciary's decisions), New Jersey Stat. Ann. Section 30-4-24.1-2 (1976 Supp.); (bill of rights for patients and retarded persons).

410. Cal. Health and Safety Code, Section 38000-38300 (West 1973).

411. Interview with Margaret Fraser, Staff Member, California Assembly Ways and Means Comm., in Washington, D.C. (Aug. 24, 1977).

412. Minn. Stat. Ann. Sec. 252A.28, .30 (1976 Supp.).

413. Mental Health Law Project, "Legal Issues in State Mental Health Care: Proposals for Change," in 2 Mental Disability L. Reptr. 61-159 (July-Aug. 1977); & 2 Mental Disability L. Reptr. 267-354 (Sept.-Dec. 1977).

414. American Bar Association Commission on the Mentally Disabled, Advocacy for Developmentally Disabled Persons (Discussion ed., Developmental Disabilities State Legislative Project, Jan. 1978).

H. Group Representation

Case by case advocacy alone will not meet the special legal assistance needs of mentally retarded persons. Too many critical issues simply do not surface through case intake processes. Group legal services are particularly essential for consumers and their representatives unaware of their legal rights or intimidated from exercising them. Aside from legislative and administrative advocacy, group representation takes many forms: training of consumers, manual writing, organizing, technical assistance, community education and other means of advancing or protecting the disabled citizens' rights. These approaches can build on the work of existing advocacy organizations, such as Associations for Retarded Citizens, cerebral palsy, epilepsy and other associations and self-help groups of and for the disabled.

Recognizing their common aims and their complementary methods, legal advocates have formed close working ties with such organizations, many of which would welcome the assistance of lawyers in training their members to identify the legal rights of disabled consumers. Special legal services projects in Minnesota and Vermont have developed training materials, workshops and manuals for this purpose. This has resulted in excellent rapport between the consumer groups and the legal advocates and created a network of people knowledgeable enough to identify rights violations and interested enough to work with the projects to remedy those violations.415/ In this way, project members have developed local contacts, received invitations to speak before organizational chapters and gained credibility as trusted legal advisors in the disability community. Training sessions have focused on major areas of

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415. For further discussion of the relations with consumer organizations, see Mickenberg, "Starting a Legal Advocacy Project for Persons with Developmental Disabilities," in G. Clarke & J. Stearns (eds.), Protection and Advocacy Systems for the Developmentally Disabled 15, 19 (1977).

law, such as special education, vocational rehabilitation, Supplemental Security Income, guardianship and its alternatives and access to day activity and residential services.

Special efforts should be devoted to help disabled persons become their own advocates. Even in state institutions claiming to have "already discharged" the more mentally capable, residents remain who are eager to learn of their basic rights. Attorneys can assist in developing and reviewing materials explaining those rights, in advising individual residents of their rights and in creating techniques for informing each resident and/or representative of his or her personal rights. In accordance with Title XIX requirements,416/ each resident is to be "encouraged and assisted, throughout his stay, to exercise his rights as a resident and citizen."417/ Furthermore, the resident is entitled to "voice grievances and recommend changes in policies and services to facility staff and/or to outside representatives of his choice, free from restraint, interference, coercion, discrimination or reprisal."418/ Without the support and counsel of an outside advocate, these statements of rights will remain only empty aspirations.

Attorneys may be able to assist residents in organizing for self-government and participation on human rights committees. Group representation becomes even more imperative as the more self-reliant and assertive residents are transferred elsewhere, leaving the more vulnerable and handicapped behind.

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416. 45 C.F.R. Sec. 249.12(a)(b)(1-15).

417. Id. at Sec. 249.12(a)(B)(5).

418. Id. On judicial protection for mental patients criticizing hospital conditions, see Brown v. Schubert, 347 F. supp. 281 (E.D. Wis. 1972), No. 72-C-438 (E.D. Wis. Feb. 5, 1975); (summary judgment enjoins punitive action, transfer to a more restrictive ward or other disciplinary action for patients exercising their rights to freedom of expression) 9 Cl. Rev. 60 (1975) #14,992.

Toward this end, a legal assistance clinical program has had law students act in Human Rights Treatment Committee meetings and make recommendations to the institution's policy-oriented Human Rights Committee as residents' advocates.[419]

Group legal services for mentally retarded persons and their surrogates may include legal advice, comments on proposed regulations, technical assistance in legislative drafting, policy formation and full scale litigation. Legal services projects must, of course, reserve their efforts for matters advancing the rights and interests of those groups' disabled members and decline involvement in in-house corporate matters. Ultimately, disability organizations may devise formal group legal services plans, not unlike the pioneering efforts of the United Automobile Workers for its Chrysler Corporation workers and their families. For now, the Associations for Retarded Citizens and similar groups provide little or no direct legal assistance for their disabled constituents. By developing durable ties with, and joining the boards of these consumer organizations, legal services advocates can encourage legal interventions on behalf of the poorest and most isolated of the disabled. In essence, legal advocates need to locate a political base which can make legal reforms "stick." In doing so, they can strengthen a young consumer movement committed to real improvements in the quality of life available to mentally retarded and other disabled citizens.

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419. "The Human Rights Treatment Committee would like to extend its appreciation to you for allowing the law students, Amy Hirsch and Joan Shear, to attend its meetings and contribute to them. They acted as persistent reminders that our primary concern should be the rights and welfare of our residents. They appeared to have greater knowledge of new and old regulations regarding the institutionalized retarded than most committee members, and forced us all to be more cognizant of those regulations." Letter from the Fernald State School Human Rights Treatment Committee to Stanley Herr, June 1, 1978.

IV. ACCESS TO LEGAL ASSISTANCE

Traditional models for delivering legal services have failed mentally retarded people. In conventional private practice, the prospective client is first expected to identify a problem or constellation of problems as "legal," and is then assumed to have the information, mobility and perseverance to locate, retain and guide a lawyer to resolve the legal problem(s). The fee-for-service practitioner, in theory accessible to all, may have little interest and less aptitude for the cases of the mentally disabled. Court-appointed attorneys in a probate court, for example, were found to have waived the right to file habeas corpus petitions in 99% of 838 commitment applications, to have waived the right to file written motions in 100% of those cases and to have waived the right to jury trial in all but one case.420/ The full compensation in a typical case was $25.45. To the Wisconsin Circuit Court, which found systematic violations of petitioners' rights to due process and effective assistance of counsel, it appeared that "the Probate judges placed a higher value on disposing of the property of dead people than it did on the liberty and welfare of living citizens."421/

A. Patterns of Access

Most mentally retarded persons have never had the services of an attorney. For decades, institutional residents were admitted without a judicial hearing or the assistance of an independent advocate. A few State

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420. State of Wisconsin ex. rel Memmel and Pagels v. Mundy, No. 441-417 (Wis Cir. Ct., Milwaukee Cty., Aug. 18, 1976) (In 1 MDLR 183) app. dismissed, State ex. rel Memmel v. Mundy, 75 Wisc. 2d 276, 249 NW 2d 573 (Wis. Sup. Ct. 1977).

421. Id. at 1 MDLR at 184.

Associations for Retarded Citizens have hired a staff attorney or retained a part-time outside counsel, but seldom are these resources available for individual client representation.[422] Class action cases enmesh plaintiffs' counsel in legal and policy matters, which may leave little time for close contact with retarded clients. Some public interest law firms consciously handle individuals' cases in only the rarest circumstances. Providing legal assistance to the mentally retarded thus remains a pioneering effort, an effort borne largely by a thin wedge of legal services and other public interest lawyers.

Only a tiny number of mental retardation facilities have any organized legal services available to residents. Those services characteristically rely on part-time legal staff who often make little effort to publicize the existence and nature of their assistance. These law students or paralegals may face inhibitions to visiting wards, or they may choose to remain in offices waiting for referrals. Lack of resources and an often tenuous access to clients combine in channeling the advocate's activity into routinized legal aid. This reactive legal aid model often fails to uncover serious violations of residents' rights, since the most vulnerable residents may be the least able to protest.

Special advocacy projects constitute the backbone of creative and aggressive representation efforts for mentally retarded people. The availability of such assistance depends on where the client happens to

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422. Interview with Paul Marchand, Director, N.A.R.C. Governmental Affairs, in Washington, D.C. (Aug. 23, 1977).

live.423/ Legal services are, by the slightest margins, more likely to exist for institutionalized than for community-based residents, and for residents of public facilities than for those in private ones. Special advocacy projects are more apt to be found in metropolitan areas or in state capitols than in the outlying areas in which large mental retardation institutions are often located. A minority of states provide some direct or referral legal services to mentally disabled persons. Those services, however, may be restricted to indigents, or to persons subject to involuntary commitment, or to those admitted to, or facing admission to a public mental disability treatment facility. Statutory services, typically covering both the mentally ill and the mentally retarded, may allocate the bulk of agency resources to the more assertive and articulate mental health system patient.424/ Other non-governmental advocacy projects rarely have the staff or funds to cover the legal assistance needs of residents of a single mental institution. This patchwork of legal services for the mentally disabled is sufficient to demonstrate clients' needs, not to satisfy them.

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423. See generally, ABA Commission on the Mentally Disabled, Developmental Disabilities Protection and Advocacy Project, "Protection and Advocacy Systems for the Developmentally Disabled: Draft Review of State Plans," (Dec. 1977).

424. Telephone interview with Ron Soskin, staff attorney, National Center for Law and the Handicapped, formerly attorney in Mental Health Information Service, First Department (Oct. 17, 1977).

B. Barriers to Access

Mentally retarded people face multiple barriers to legal services. Poverty and mental retardation are closely linked, and retarded people who lack control over their financial assets are also in no position to hire an attorney.425/ In some areas, the eligibility guidelines for legal services are so restrictive that persons threatened with termination of pensions which just exceed guidelines cannot receive legal aid.426/ Conflicts of interest between a mentally retarded person and his or her guardian or other fiduciary may also inhibit legal representation of the person under a disability.427/ Moreover, the vast majority of well-intentioned parents may simply be unaware that the problem of obtaining services for a mentally disabled offspring is susceptible to a legal solution.428/ Many legal service offices are physically and psychologically inaccessible to retarded and other disabled persons.429/ People labeled as mentally retarded may have communication

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425. See generally, R. Hurley, Poverty and Mental Retardation: A Causal Relationship (1969).

426. Letter from Jonathan A. Zimring, Project Director, Georgia Mental Disability Law Project, Inc., to author, Oct. 17, 1977.

427. The conflicts and the need for separate representation where they arise are by no means unique to mentally retarded persons and their families. See, e.g., Note: "Lawyering for the Child; Principles of Representation in Custody and Visitation Disputes Arising from Divorce," 87 Yale L.J. 1126, 1135 (1978); Custody of Minor, Mass. Adv. Sheets, 2002, 2025 (Mass. Sup. Jud. Ct., 1978) (parental rights do not clothe parents with life and death authority). Herr, "Civil Rights, Uncivil Asylums and the Retarded," 43 Cin L. Rev. 679, 708-721 (1974).

428. Kay, et al., "Legal Planning for the Mentally Retarded: the California Experience, 60 Cal. L. Rev. 438, 490 (1972).

429. Proposal from Paul Hearne, Executive Director, Handicapped Persons Support Unit, New York City, to the Legal Services Corporation.

skills which vary from non-existent to conventional.[430] Without training in understanding their rights, using telephones or writing letters of complaint, even borderline retarded people may be unable to exercise their right to counsel. Those in institutions - in addition to all these other barriers - live in closed environments which further limit contacts between lawyers and prospective clients. Defensive institutional staff may do all they can to prevent or frustrate those contacts.

Congress has, at least twice, legislatively recognized the substantiality of these barriers. In identifying handicapped individuals as experiencing "special difficulties of access to legal services,"[431] the 95th Congress acknowledged that there are particular groups of eligible clients who can be "reached only through outreach activities."[432] The Legal Services Corporation Act Amendments of 1977 reaffirmed the ethical obligation of legal services lawyers to undertake community education and outreach to inform the poor of their rights.[433] P.L. 94-103 shared the same premise, perceiving aggressive advocacy as a vital means by which "one of our most ignored

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430. See, e.g., *Superintendent of Belchertown State School* v. *Saikewicz*, Mass. Ad. Sh. 2461, 2466 (1977):

> Saikewicz "was not, however, able to communicate verbally -- resorting to gestures and grunts to make his wishes known to others and responding only to gestures or physical contacts."

431. 42 U.S.C. Sec. 2996(a)(2)(c), as amended P.L. 95-222, Dec. 29, 1977.

432. "Legal Services Corporation Act Amendments of 1977" S. Rep. No. 95-172 at 13.

433. *Id.* See also, Note: "Outreach: Bringing the Eligible into Federal Assistance Programs," 62 *Corn. L. Rev.* 1093 (1977); *In re Primus*, _____ U.S. _____ 46 L.W. 4519 (May 30, 1978).

minorities - the mentally retarded - are protected under law at last."434/ Accordingly, the Developmental Disabilities Assistance and Bill of Rights Act sought to curb abuses of institutional residents and provide them with legal remedies. Senator Harrison Williams, one of the Act's main architects, cogently explained this legal advocacy thrust:

> All indications point toward little change, unless substantial legal and advocacy pressure is forthcoming. While much can be said about the lack of funds to improve conditions at these institutions, at some point this country must draw the line. The abuses are too commonplace to point at a single institution or a single abuse and say that is an anomaly. Over the last two years the Committee. . . has taken testimony or received reports of: Inappropriate admissions because of lack of community services, inappropriate and inhumane experimentation with residents, sterilizations and other operations performed for convenience of treatment, starvation and malnutrition, abuse and physical punishment, inadequate food and living conditions, and death.435/

C. Client Access to Legal Advice and Assistance

It took Kenneth Donaldson 19 appeals and four shots at the United States Supreme Court before this articulate white male won his freedom from state mental confinement.436/ None of his prior petitions to state and Federal courts for release were ever resolved on the merits or set down for evidentiary hearings. The *pro se* efforts failed, but Donaldson persisted, and in the end found leading counsel to marshal his strategy to personal

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434. Remarks of Senator Javits, manager of P.L. 94-103, the Developmental Disabilities Assistance and Bill of Rights Act, Cong. Rec. S.16549 (Sept. 23, 1975).

435. Cong. Rec. S.9362 (June 3, 1975).

436. Civil Rights of Institutionalized Persons: Hearings on S.1393 Before the Subcomm. on the Constitution of the Senate Comm. on the Judiciary, 95th Cong., 1st. Sess. at 85 (1977) (Statement of Donaldson).

liberty.437/ What of those who are too young, too infirm, too uninformed to find any, let alone specialized, legal assistance? More troublesome, still, are the truly mentally retarded institutional residents who may be unable to protest, or even to comprehend or communicate the day-to-day indignities of back-ward life. Here, lawyers rarely venture. And here are found the starkest human and legal needs. But the lawyer is a stranger in this very strange land, and the traditional niceties of legal etiquette will hardly equip one for serving clients who might sooner eat a lawyer's calling card than read it.

It is not enough that mentally retarded persons have the right to request the assistance of counsel. The right is a hollow one if its beneficiary, or that beneficiary's family or friends have no notice of it, or have no practical experience in calling upon the assistance of legally-trained people. Time and again, legislatively or judicially created entitlements for the mentally disabled are rendered meaningless by a failure to publicize those new rights on a community level, and to follow up with explanations on an individual level.438/ Advocates and their programs must find ways affirmatively to educate the client community as to these disability rights and the availability of legal aid services to resolve a host of socio-legal problems.

Residents of mental retardation institutions may be entitled to specific assistance in the exercise of their rights. State laws and regulations may

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437. O'Connor v. Donaldson, 422 U.S. 563 (1975), K. Donaldson, Insanity Inside Out (1976).

438. R. Weatherley & M. Lipsky, "Street-Level Bureaucrats and Institutional Innovation: Implementing Special Education Reform in Massachusetts" (unpublished paper delivered at Am. Pol. Science Ass'n., 1976 Annual Meeting, Sept. 2-5, 1976). (First year implementation of Ch. 766 marked by state-wide failures of planning, coordination and adequate public information).

impose obligations on departmental employees and others to assist residents in communicating with outsiders, including lawyers, judges and others who might aid in resolving a resident's complaint.439/ To leave that obligation to institutional staff plainly does not go far enough. Human rights committees and in-house ombudsmen may, similarly, be too tied to an administrative orientation to be relied upon as brokers to attorney-client connections. Even well-meaning institutional insiders will be under considerable pressure to resolve residents' rights issues internally and, above all, to avoid the press and courts. Courts need to be aware of impediments to residents' access to the judiciary and the possibility of ordering advocacy services for mentally disabled persons who would otherwise lack the effective assistance of counsel.440/

The typical mental institution has no "jailhouse" lawyer. It has no law library for inmates or staff, nor any practical substitute for these missing resources.441/ If it should create a "Civil Rights Officer," that position is likely to be an "add-on" to some staff professional's real job. In exceptional circumstances, if the institution should hire a lawyer, that

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439. S. Brakel & R. Rock (eds), The Mentally Disabled and the Law 155-58 (1971 Rev'd Ed); Mass. Gen. Laws Ch. 123 s. 23; 4 Mass. Code of Human Services Regs, s. 221.13 (Dec. 5, 1974): "the superintendent or other head of the facility shall designate a person or persons employed by or affiliated with such facility as a Civil Rights Officer, to be responsible for assisting patients in the exercise of their rights."

440. See, Mental Patients Civil Liberties Project v. Dept. of Public Welfare, No. 73-1512 (E.D. Pa. April 14, 1975); (consent decree approved giving Project access to Haverford State Hospital; providing as matter of departmental policy that Patients' Rights Organizations have right to peaceful assembly, to organize a patient/resident government, to receive visitors daily, including civil rights group representatives, and to retain and see an attorney at any time). On cases granting attorneys access to migrant labor camps, see Fox v. Kundt, No. 2738 (E.D. Wash. Dec. 11, 1974).

441. But see, Matukia v. Beal, (W.D. Pa., filed Jan. 3, 1977), (pro se petitioner in mental hospital requests access to law library).

person will be called upon to defend institutional practices, counsel employees and prosecute grievances against staff.442/

Residents' complaints seldom, if ever, are passed to outside attorneys. A California Residents' Rights Advocate described her in-house position as "a joke," noting that her bosses in the State Department of Health do not want cases referred to lawyers.443/ Furthermore, institutional staff are likely to have only a dim idea of the contours of residents' rights. This muddled comprehension arises from an array of departmental rules, regulations, policy statements, guidelines and memos, all basically inconsistent with the institution's own practices and policy manuals and perhaps, conforming still less to state and Federal laws, regulations and judicial decrees. Moreover, for months on end even the most basic departmental regulations can remain unknown and undistributed to direct care and other staff.444/ It is not surprising that staff is of little assistance to residents in anti-discrimination, civil disabilities, Social Security and a wide range of other basic residents' rights.

Institutional staff are the wrong people on whom to cast the responsibility for notifying inmates of their rights. A California Supreme Court decision recognized "the possibility of role conflict arising from entrusting the notice and explanation of rights function to the same agency

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442. Telephone interview with Alston Vander Horst, staff attorney, Legal Services of Nashville, formerly patients' advocate in Dept. of Mental Health state hospital (Sept. 19, 1977). While such attorney-advocates were in four state mental hospitals, none were assigned to mental retardation institutions.

443. Anonymous interview, in Orange County, California (June 16, 1978).

444. In Massachusetts, for example, new regulations promulgated in February 1978 were not distributed to key institutional staff until June, and then only after extensive advocacy pressure from advocates of the Harvard Law School clinical program. See note 419, supra.

which undertakes to perform the therapeutic function."445/ The unanimous court in Thorn therefore concluded that any certification of a person as gravely disabled or otherwise mentally disordered, should trigger appointment of counsel or other suitable safeguards to protect the patients' rights to counsel and to seek release on habeas corpus.446/ A recent Massachusetts statute adopts the same principle in requiring that voluntary patients have a right to legal advice and notification by counsel of their rights and legal status.447/ This law, however, has been subverted by the staff of at least one institution who routinely find that voluntary patients "waive" this right to counsel.448/ Yet, as noted in the Thorn case, patients may be fearful of signing or putting an "X" to a piece of paper, or may face emotional distress or sedation, making informed waiver improbable. "Absent an understanding by the patient of the nature of his detention and of his rights, it is difficult to perceive how he could knowingly decide whether or not to exercise them."449/

The reasoning behind Thorn is all the more applicable to mentally retarded residents lacking the training, comprehension or communication skills

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445. Thorn v. Superior Court, 1 Cal. 3rd 666, 675, 464 P.2d, 56,62 (Sup. Ct. 1970).

446. On the failures of appointed counsel in conservatorship proceedings, see Morris, "Conservatorship for the 'Gravely Disabled': California's Nondeclaration of Non-independence," 15 San Diego L. Rev. 201 (1978).

447. Mass. Sess. Laws, Ch. 356 of 1976. amending Mass. Gen Laws, 123 S. 10(a) "Prior to accepting an applicaton for a voluntary admission, the superintendent shall afford the person making the application the opportunity for consultation with an attorney, or with a person who is working under the supervision of an attorney, concerning the legal effect of a voluntary admission."

448. Interview with Steven J. Schwartz, Managing Attorney, Mental Patients Advocacy Project in Northampton, Mass. (November 8, 1977).

449. Thorn, supra note 445, at 668.

to request a right to counsel. Indeed, even more sophisticated penal inmates and psychiatric patients may be incapable of defining their needs for legal assistance.450/ Given stereotypes of the lawyer's role as a courtroom advocate for the alleged criminal, retarded inmates may not even know which of their problems are susceptible to legal resolutions or the assistance of law-trained personnel. Perry Mason and his current TV successors are known to mildly and moderately retarded institutional residents; lawyers who help with SSI, educational rights and institutional "privileges" are not. Yet, almost all mentally retarded residents have need of such legal assistance.451/

Several Federal programs require assurances that disabled consumers and their surrogates have affirmative notification of their rights. Title XIX regulations require that Intermediate Care Facilities for the Mentally Retarded advise residents and their guardians of a constellation of basic rights.452/ Medicaid surveyors, as part of the process of certification of ICF-MR facilities for Federal reimbursement, are to determine the adequacy of

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450. Dickey and Remington, "Legal Assistance for Institutionalized Persons -- An Overlooked Need," 1 *So. Illinois U.L.J.* 175, 177 (1976). *Fasulo* v. *Arafeh*, 39 Conn. L. J. 1, 3, 5 (Conn. Sup. Ct., Sept. 20, 1977) (due process requires state-initiated periodic judicial review). In noting "the difficulties of overcoming an isolated environment" in challenging civil confinement, the Court reasoned:

> ...we cannot assume that friends and allies will always be available to secure counsel and marshall evidence on the patient's behalf. Nor can we assume that even if a patient is notified of his right to pursue any of the available remedies, he will be adequately protected.

451. See generally, Brakel, "The Role of Lawyers in the Mental Health Field," 2 *A.B.A. Foundation Research J.* 467 (1977).

452. Social Security Act, tit. XIX, 42 U.S.C. Section 1396, 45 C.F.R. 249.12(a)(B)(1-15) (March 18, 1974).

those rights, statements, notifications and safeguards.453/ The Education for All Handicapped Children Act requires that the states arrange for surrogates for children without familial support who are eligible for special education.454/ Those surrogates must be independent advocates and may not be employees of school authorities.455/ Similarly, P.L. 94-103 calls for independent advocacy and protection for developmentally disabled persons of all ages, wherever they live.

These advocacy roles cannot be performed as neutral information services. Instead, they represent potential wedges that may be used by legal services programs to gain entry to institutions and to contact residents in need of explanations of their rights. One director of a mental retardation institution publicly urged that links between residents and community legal

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453. U.S. Department of H.E.W., "Interim Supplemental Form for Surveying ICF Residents' Rights," attached to memorandum from Linda Glenn, Assist. Commissioner of the Massachusetts Department of Mental Health to Superintendents & Regional Services Administrators, Sept. 22, 1977. In accord with 45 C.F.R. 249.12(a)(1)(ii)(B), facilities must "Ensure that each resident admitted to the facility; (1) is fully informed of his/her rights and responsibilities as a resident and of all rules and regulations governing resident conduct and responsibilities. Such information is provided prior to or at the time of admission or, in the case of residents already in the facility, upon the facility's adoption or amendment of resident right policies, and its receipt is acknowledged by the resident in writing; and in the case of a mentally retarded individual, is witnessed by a third party."

454. 20 U.S.C. Sec. 1415. The surrogate is to represent the child in identification, evaluation and educational placement processes for any child who is a ward of the state, or whose parents or guardian are unknown or unavailable.

455. Id. See generally, O'Donnell, "An Advocate's View: The Role of the Surrogate Parent," Amicus 28 (June 1977). Note, however, that the statute refers only to a surrogate, not a surrogate parent, and hence the advocacy function may also be conducted by paralegals and other lay advocates.

services be implemented "with all possible speed."456/ His position has nationwide implications:

> Legal assistance immediately available and onsite can increase the likelihood of our clients obtaining needed community placement and community services. Without increased availability of community placement and community services I see no immediate end to the current crisis in the State Hospital system due to lack of programming and staffing. If we desire to change our system to insure its continuance, we must have the availability of onsite legal assistance and advocacy for our clients.
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> I believe that the question of participation of the community legal system in the affairs of developmentally disabled clients in State Hospitals has already been settled. There is no way, nor would it be appropriate, to interfere in the development of this needed association.457/

D. Attorney Access to Mentally Retarded Clients

Lawyers for mentally retarded persons have an affirmative obligation to reach out to clients who cannot reach out to them. In discharging that obligation, those lawyers, paralegals and other agents have a legitimate interest in visiting mental institutions and talking with residents.458/ Remarkably few attorneys avail themselves of opportunities to visit mental retardation wards, or to otherwise press for inspection of the facilities in

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456. Letter from Michael J. Levine, M.D., then Clinical Director, Fairview State Hospital to Raymond Procunier, California Dept. of Health, Nov. 18, 1976.

457. Id.

458. Bartley v. Kremens, No. 72-2272 (E.D. Pa . June 21, 1977). See also cases upholding the right of lawyers to visit residents of migrant camps and nursing homes to advise them of their rights. Peterson v. Talisman Sugar Co., 478 F. 2d 73 (5th Cir. 1973). Folgueras v. Hassle, 331 F. Supp. 615 (W.D. Mich. 1971). See cases at note 440 surpa.

which clients live or work.459/ For the most part, advocates have been reactive rather than proactive in their client contacts.

The legal profession has a duty to make information available to those segments of the public ignorant of their rights.460/ In regard to the mentally retarded - a classic example of a group largely uncomprehending of their rights - only a handful of programs and advocates take that duty seriously. There are several ways of carrying out that task. Ties to consumer organizations, such as associations for mentally retarded, epileptic, autistic, learning disabled or other disabled individuals, provide an efficient way to publicize legal entitlements and to make the availability of legal services for special populations known. If lawyers will sit on their boards, as well as governmental affairs and legal advocacy committees, those organizations could be mobilized to press for new laws, lobby for administrative reforms and join or initiate litigation.461/ Public speaking before conventions, consumer groups or care providers also has generated legal

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459. According to questionnaire results, the most common methods of obtaining clients were referrals, client walk-ins, public contacts and consumer group liaisons. Far fewer advocates reported walking wards or visiting facilities as a source of client contact. Only 15 advocates had ever made use of a part-time or full-time office in a mental institution. Appendix A.

460. ABA Code of Professional Responsibilty, EC 2-1; D.R.2-104(A)(2) (1976):

> "...far too many persons are not able to obtain equal justice under law. This usually results because their poverty or ignorance has prevented them from obtaining legal counsel." Address by E. Clinton Bamberger, Association of American Law Schools 1965 Annual Meeting, Dec. 28, 1965, quoted Id. at 13, note 3.

461. On roles for disability organizations in supporting legal advocacy, see Gilhool, "The Uses of Courts and Lawyers," in President's Committee on Mental Retardation, "Changing Patterns in Residential Services for the Mentally Retarded, 155, 173-75 (Rev. Ed. 1976); Lippman, "The Public", Id. at 95, 97-101.

assistance activity. The hiring of community organizers or community education coordinators can also promote greater understanding and assertion of rights of the disabled. Newspaper articles, TV or radio announcements and other media efforts can publicize those rights. Advocacy programs, for example, have distributed brochures explaining how they help people with developmental disabilities "get the rights and services you are entitled to under the law."462/

Old barriers to advertising and solicitation have fallen. Lawyers providing free legal assistance through non-profit agencies can make these services known to potential clients.463/ This is particularly vital for developmentally disabled persons, some of whom may be incapable of defining their legal needs or may be intimidated from contacting pro bono or other attorneys willing to serve them.464/ A recent order of the Utah Supreme Court enables a private non-profit corporation to "hold itself out to the public by advertisement. . . to render legal services or advice of any kind in any action or proceeding, or to solicit directly or indirectly any claim or demand for the purpose of bringing action thereon as the same relates to the

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462. New Jersey Office of the Public Advocate, "What is a Developmental Disabilities Public Advocate?" (1977 brochure).

463. ABA Code of Professional Responsibility, D.R. 2-104 (A)(2) (1976). See ABA Formal Opinion No. 148 (November 16, 1935) in ABA opinion of the Committee of Professional Ethics 418 (1967) (The ban on solicitation was never aimed at lawyers willing to devote some time to "The interest of indigent citizens whose constitutional rights are believed to be infringed.") Mass. Bar Assoc., Comm. on Admin. of Justice, Subcomm. on Ethics, Opinion No. 74-5 (June 20, 1974). (Lawyers affiliated with a Federal non-profit legal assistance project may interview prison inmates scheduled for parole revocation hearings, advise such inmates of their rights and then undertake to represent those indigent inmates who desire legal representation at the hearing.)

464. Letter from Dan Walker to author, August 19, 1977, regarding his law firm's program of pro bono assistance to persons with epilepsy. See generally, Bates v. State Bar of Arizona, 433 U.S. 350 (1977). In re Primus, 4360. S. 412 (1978).

protection of rights and advocacy for persons with developmental disabilities. . ."465/

Under the Developmental Disabilities Act, the protection andadvocacy systems were clearly intended to intervene sua sponte in matters of suspected rights violations. Section 113 projects were granted the authority to pursue the legal, administrative and other remedies of persons who might be unaware or powerless to protest violations of their legal and human rights.466/ Advocates outside "the established delivery system" were thus empowered to make an "examination of situations in which (the disabled person's) rights as an individual citizen may be being violated."467/To investigate and otherwise defend the imperiled rights of developmentally disabled persons, these advocacy agencies must have access to those persons, residential facilities, attending staff and records.468/

State statutes can facilitate that access to vulnerable disabled persons. The Massachusetts Mental Health Legal Advisors Committee, through attorneys associated with the Committee, may, upon third-party referrals, provide legal assistance to persons unable to give informed consent to representation. While most institutionalized clients are able to enter into an attorney-client relationship, this exceptional power, sparingly used, enables severely retarded persons and others to receive legal aid.

Operating under the aegis of the Supreme Judicial Court, the Committee

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465. Utah Legal Services for the Developmentally Disabled, Inc., Minutes of Special Meeting of the Governing Board, (Nov. 16, 1977, unpublished minutes).

466. 42 U.S.C. Section 6012 (Supp. 1976) (P.L. 94-103, Section 113).

467. S. Rep. 94-160, 94th Cong., 1st Sess. at 38 (1975).

468. See Herr, Advocacy under the Developmental Disabilities Act (1976); ABA Comm'n. on the Mentally Disabled, Advocacy for Developmentally Disabled Persons 27 (1978 Discussion Edition). Laski, "Authority to Pursue Remedies: An Issue Paper," in L. Baucom and G. Bensberg, Advocacy Systems for Persons with Developmental Disabilities 277 (1977).

appoints legal advisors and organizes a program of legal assistance to patients and residents of mental retardation and health facilities in the Commonwealth. These legal advisors are empowered to interview patients and residents, "examine all records pertaining to such patient or resident," and make "all necessary inquiries" in representing them.469/ State funded and operated agencies, such as the New York Mental Health Information Services (MHIS) and the New Jersey Department of the Public Advocate, exist so that, in theory, any indigent resident or patient can receive some legal assistance and advice. Oriented to psychiatric patients and the commitment process, MHIS units have had difficulty finding an effective role for themselves in relation to mentally retarded residents.470/ The Ohio Legal Rights Service and the Office of Advocacy for Developmentally Disabled Persons of the Department of the Public Advocate have been more creative. They have pursued a wider range of residents' interests and have proved willing to use class action and other impact forms of litigation in addition to informal solutions.471/

Legal services projects have negotiated access agreements to serve clients of mental facilities. Typically, those agreements provide advocates

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469. Mass. Gen. Laws Ch. 221, Section 34 E. For a useful collection of state materials, see Mental Health Legal Advisors Committee, *Lawyers Reference Manual* (1977).

470. Letter from Ronald M. Soskin, formerly MHIS First Department attorney based at Manhattan Developmental Center, currently staff attorney, National Center for Law and the Handicapped, Inc., Oct. 25, 1977.

471. See e.g., *Siddles* v. *Delaney*, No. C75-300A (N.D. Ohio, April 26, 1976). *Barbara C.* v. *Moritz*, No. C2-77-887 (S.D. Ohio, filed Nov. 17, 1977). *In re C.S.*, Docket No. HNCC 11-75 (Law Div. Hunterdon Cty, 1975); (right to treatment, habilitation & periodic review for retarded resident). For other cases litigated by the Public Advocate's Division of Mental Health Advocacy, see *In re Geraghty*, 68 N.J. 209 (Sup. Ct., 1975); (right to counsel at commitment hearings & periodic reviews); *Carroll* v. *Cobb*, 139 N.J. Super. 439 (App. Div. 1976); (right to vote for residents of state school for the retarded); *In re Alfred*, 137 N.J. Super. 20 (App. Div. 1975); (right to independent psychiatric examination at county expense) *Board of Chosen Freeholders* v. *Connell*, 9 Clearinghouse Rev. 585, 732 (1975 & 1976) (right to control assets while institutionalized).

with office space in institutions, office furniture and telephone service, as well as providing access to clients, their records and living areas.[472] After an initial honeymoon phase, several Bar-supported projects report attempts by mental health administrators to renegotiate or cancel those agreements.[473] While continuing to represent clients, those projects spend considerable energy fighting to honor or renew those access agreements. Other projects, such as the Yale Law School's clinical legal aid program at Connecticut Valley Hospital or the American Bar Association's demonstration advocacy project at Norristown State Hospital, have operated for several years, notwithstanding the adversarial advocacy stances they adopted. Tension between mental institutions and aggressive advocates for mental patients is inevitable. Only the diplomatic skills of advocates and the support of friendly administrators have kept alive legal projects bold enough to file class action claims or to press patients' claims vigorously through the system. Federal as well as state legislation is needed to ensure the survival of such projects and attorney access to clients.

This tension is keen in states which resolve access issues through contracts between state government and legal services agencies. For several years, Washington State and Vermont have funded legal assistance for hospitalized mental patients and others through legislatively appropriated monies. Through a network of eight offices across Washington, the Institutional Legal Services Project of Evergreen Legal Services serves people in mental hospital and penal, juvenile and mental retardation institutions.

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[472] See, e.g., Memorandum of Agreement for Civil Legal Services to Indigent Patients at Dorothea Dix Hospital, Wake County Bar Association Committee on the Mentally Disabled, August 27, 1976.

[473] Interviews with John Decker and Mary Ann Bannan, in Washington, D.C. (Dec. 16, 1977).

The mental retardation office in Seattle, with only one lawyer and one paralegal attempts to meet the legal needs of some 3500 institutional residents in four remotely located facilities. Vermont Legal Aid, which for several years has operated a part-time office in a state mental hospital, now has obtained funds for legal services to residents of the Brandon Training School for the retarded. Given their political vulnerability, these projects may be subject to abrupt funding terminations or to performing routine legal tasks which leave little time for attorneys to engage in more systemic legal advocacy for inmates.474/

Lawyers have various methods for raising the claims of uncomprehending and unrepresented residents. By statute or by-laws, section 113 and other entities acting in behalf of retarded persons may be authorized to sue or otherwise institute remedial proceedings for institutional residents.475/ For example, a New Mexico attorney is counsel of record for all 400 residents of the state's largest mental retardation institution by virtue of responses of next-of-kin to a letter from the institution and a stipulated order of appointment.476/ Class actions by Associations for Retarded Citizens and

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474. See, e.g., "Prisoner Legal Assistance Project in New York Facing Cuts in Funds," New York Times, B11, Col. 1, Feb. 6, 1978 (N.Y. legislative proposal to reduce inmate legal service funds and assign parole reponsibilities to project).

475. Barbara C. v. Moritz, No. C2-77-887 (S.D. Ohio, filed Nov. 17, 1977); (Ohio Legal Rights Service filed suit as best friend for 2,000 residents). In re Arlene D., 335 N.Y.S. 2d 638 (Fam. Ct., Richmond Cty., 1972); (Society for Prevention of Cruelty to Children asserted child neglect claims for children at Willowbrook State School).

476. Telephone interview with Marianne Bennett, Director of Community Services for the Handicapped, Legal Representation Project at Los Lunas State School (Feb. 23, 1978). Some 1/3 to 1/2 of the residents' nearest relations responded by mail or phone, none refused counsel, and the Attorney General's Office stipulated to an order that Ms. Bennett represent residents with non-responding relations. In re Residents of Los Lunas Hospital and Training School, No. 111-Misc., Stipulation and Appointment of Counsel (N.M. Dist. Ct. Valencia Cty., filed Feb. 1, 1978).

similar groups have affirmatively raised an array of legal claims to education, habilitation and other services for otherwise unrepresented disabled persons.477/ Individual lawsuits on behalf of retarded or incompetent persons have proceeded through a wide variety of "next friends," including lawyers,478/ lay advocates,479/ clergymen,480/ Congressmen,481/ special educators482/ and welfare rights organizations.483/ In each of these cases, the person under a legal disability was permitted his or her day in court and a resolution on the merits. Lawyers acting as guardians *ad litem* for allegedly incompetent persons have also protected their wards' interests in matters of proposed sterilization, abortion and guardianship.484/

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477. See e.g., *Pennsylvania Association for Retarded Children* v. *Pennsylvania*, 334 F. Supp. 1257 (E.D. Pa. 1971); *Maryland Ass'n. for Retarded Children* v. *Maryland*, Equity No. 77676 (Md. Cir. Ct., Baltimore Cty., 1974) *New York State Ass'n. for Retarded Citizens* v. *Rockefeller*, 357 F. Supp. 752 (E.D. N.Y. 1973), *Frederick L.* v. *Thomas*, 419 F. Supp. 960 (E.D. Pa. 1976), aff'd. 557 F. 2d. 373 (3rd Cir. 1977) (identification and educational rights of learning disabled). *North Carolina Ass'n. for Retarded Citizens* v. *North Carolina* C.A. No. 3050 (E.D.N.C., filed May 18, 1972).

478. *Kaimowitz* v. *Dept. of Mental Health*, No. 73-19434-AW, (Cir. Ct. Wayne Cty. Mich., July 10, 1973).

479. *Brewster* v. *Dukakis*, No. 76-4423-F (D. Mass., filed March 15, 1977).

480. *D.C. Welfare Rights Organization* v. *Thompson*, No. 71-1150-J (D.C. Super. Ct., June 18, 1971); *Mills* v. *Board of Education*, 348 F. Supp. 866 (D.D.C. 1972).

481. *Mills*, *id*. (Congressman Ron Dellums).

482. *Saville* v. *Treadway*, 404 F. Supp. 430 (M.D. Tenn. 1974) (Robert Audette). See also *In re D.* (a minor) (1976) Fam. 185 (U.K.); *Patton* v. *Dumpson*, 425 F. Supp. 621 (S.D.N.Y. 1977).

483. *D.C. Welfare Rights Organization* v. *Thompson*, *supra* note 480.

484. See e.g., *Superintendent of Belchertown State School* v. *Saikewicz*, Mass. Adv. Sh. 2461 (Sup. Jud. Ct. 1977) (chemotherapy for a profoundly retarded adult declined); *Ruby* v. *Massey*, No. 76-315, Summary Judgment Ruling, at 12 n. 18 (D. Conn., May 16, 1978); *Horacek* v. *Exon*, 357 F. Supp. 71 (D. Neb. 1973) (guardian *ad litem* appointed to protect interests of retarded class members in action brought by parents' association).

Determined lawyers, in short, can find ways to reach even the most secluded client. Repeat players will learn easier routes to those clients and will have a sufficient stake to develop rules, agreements and understandings which keep those routes open. By building relationships with institutional staff, state officials and consumer groups, advocates can minimize the mistrust and harassment which other lawyers unaccustomed to work in this setting often face. Attorneys who are aggressive advocates for their clients may find litigation the only means to keep open their access to institutionalized persons.[485] In most mental retardation facilities, however, it is not the problems of access, but of attorney disinterest that pose the most pervasive barrier to legal assistance.

E. Advocacy Projects for Retarded and other Developmentally Disabled Persons

Specialist projects are essential if legal advocacy assistance for retarded persons is to be more than episodic. Only a handful of offices focus on the entitlements of mentally retarded and other developmentally disabled persons. Projects like the Minnesota Developmental Disabilities Advocacy Project, the Ohio Legal Rights Service and the Vermont Developmental Disabilities Project demonstrate the feasibility and necessity of state-wide approaches to probe a novel and complex legal terrain. Lawyers with these projects have the staying power to solve access questions and to turn their resolutions to the advantage of their clients. Programs serving both mentally ill and mentally retarded persons have a tendency to become preoccupied with the civil commitment and other problems of the more articulate, vociferous or persistent "mental health" cases. This disparity needs to be corrected. As a former Mental Health Information Service attorney explained, "By defining the functions, setting basic policies and establishing a working philosophy, the retarded area could achieve parity with the mental illness area within the agency."486/ Legal advocacy programs, such as the Mental Patients Advocacy Project at Northampton State Hospital, the Mental Health Advocacy Project in Los Angeles, and the Institutional Legal Services Project in Seattle, attempt to establish that parity and provide an advocacy presence for both mentally ill and retarded institutional residents. Specialist projects may also be the most efficient delivery system for providing traditional "non-consumers" of legal services with comprehensive advocacy: direct representation, monitoring, legislative advocacy, affirmative outreach, back-up and technical assistance to consumer groups and lay advocacy organizations.

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[485] Bartley v. Kremens, No. 72-2272, Order of June 21, 1977 (E.D. Pa.) (access to medical records, interviews of class members, confidential telephone calls, access to living units at reasonable times, by David Ferleger and all law students and paraprofessionals working with him). See Procunier v. Martinez, 416 U.S. 396 (1974).

Projects can fix on the needs of the real clients in interest and train lawyers to identify those clients and those needs. These are no simple matters in a context in which the law is highly technical, the cases pose uniquely challenging jurisprudential and ethical issues and the target agencies wield great power over clients' lives. An assumption that any court-appointed lawyer will do justice to the mentally retarded client is patently mistaken. The debasement of a right to counsel in civil commitment or guardianship cases should provide sufficient caution against worshipping the right to counsel without addressing the service delivery questions.487/ In

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486. Letter from Ronald M. Soskin, supra note 470.

487. Andalman & Chambers, "Effective Counsel for Persons Facing Civil Commitment; A Survey, a Polemic and a Proposal," 45 Miss. L.J. 43 (1974), Morris, "Conservatorship for the Gravely Disabled," 15 San Diego L. Rev. 261 (1978). Houseman, "Equal Protection and the Poor," 30 Rutgers L. Rev. 887, 892-93 (1977).

projects in which third-person referrals are the rule rather than the exception, project staff must always view the disabled person as the principal client. All counselling, advice-giving and other informational activities should advance that client's interests. In one project, attorneys in initial interviews advise the disabled person, parent or other third-party referral source that the attorney's paramount loyalty is to protect the rights and interests of the developmentally disabled person.488/ Should conflicts of interest subsequently arise, project staff advise that the third-party may have to seek outside assistance of counsel. Special care should also be taken when referrals come from service providers. Advocates clearly must not become the legal advisor to both providers and consumers, unless the service agency directly advances or supports the disabled client's interests. Mental disability advocates must be wary of taking over social work functions delegated by institutional staff, or the role of institutional counsel vacated by remote or unhelpful state lawyers. These are important roles, but they are not those of a resident's advocate.

The disabled client's right to choose is the legal advocate's starting point. Advocates must take the time to elicit the client's feelings, comments and directions on proposed courses of action, even where a client's mental or physical condition clouds capacities for considered judgment.489/ As the Code of Professional Responsibility states: "If the client is capable of understanding the matter in question or of contributing to the advancement of

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488. Interview with Marcia Burgdorf, Director, Maryland Developmental Disabilities Law Clinic, University of Maryland Law School, (December 13, 1977).

489. Even if the client were totally lacking in communicative abilities (e.g., in a coma), it would be necessary for the attorney to observe the client's living conditions, and helpful to talk with those who care for the client.

his interests, regardless of whether he is legally disqualified from performing certain acts, the lawyer should obtain from him all possible aid."490/ The great majority of mentally retarded clients can provide some aid. For a tiny minority, interested parents, relatives or guardians may be empowered to act, providing their specific acts are in the ward's best interests. For other clients - incompetent in fact but lacking surrogates, no visitor, friend or fiduciary may be in sight.491/ In that zone, for the very young, the very old or the very impaired, advocates may find guidance from organizations of the disabled and in the human rights consensus traced in earlier sections.492/

Client-oriented projects should resist the temptations of abandoning adversary roles for "best interest" helping roles. Project staff can help each other to work from the client's assessment of his or her own needs, rather than in substitution of the client's expressed wishes. They can discuss, ruminate upon and formulate explicit policies in circumstances under which canons of control by an autonomous client do not fit the realities of a case. How does an attorney represent a profoundly retarded individual who can barely communicate or comprehend such abstract concepts as "legal rights," "informed consent," or "violation of rights?"493/ How does an advocate pro-

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490. American Bar Association, Code of Professional Responsibility EC 7-12 (1976).

491. For example, 43% of Pennhurst residents have had no family contact within the last three years. Halderman v. Pennhurst State School, 446 F. Supp. 1395, 1402 (E.D. Pa. 1977).

492. See discussion at Section II. A-B, supra.

493. See Superintendent of Belchertown State School v. Saikewicz Mass Adv. Sheets 2461 (Sup. Jud. Ct. 1977).

tect his or her client from imprudent choices without being dominating?494/ How are possible conflicts with family members handled when a project undertakes to represent a disabled member who already has few outside ties to conserve?495/

The answers are inseparable from the specific factual contexts in which these questions arise. Advocacy projects, through governing and advisory boards, can, however, share the responsibility for articulating guidelines and surfacing problems of advocates slipping "out of role." They can alert advocates to the hazards of signing up as a member of a "helping team" alongside medical doctors, social workers, psychologists, psychiatrists and attendants. In this already overwhelming interdisciplinary phalanx, the resident needs a partisan, not a paternalistic lawyer. This above all requires an attorney with the sensitivity and patience to listen carefully to the disabled client and to reflect that client's preferences as best she or he can. Drugs, fear, physical illness or limited intelligence may make it more difficult for the resident to formulate, communicate and foresee the consequences of his choices and for others to ascertain, report and act upon those choices. Mentally retarded individuals are entitled, however, to the dignity of taking some risks and to the services of advocates who will defend that dignity.

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494. Lawyers have obligations to counsel clients as to a range of alternatives or to point out the foreseeable consequences of ill-considered choices.

495. Interview with Nancy Rich, Mental Health Legal Advisors Comm. (Feb. 17, 1978), who reminded me that to a mentally retarded resident of a state school, a mother's twice yearly visit can be of enormous value.

V. PRIORITIES AND THE ROAD AHEAD

Without sustained advocacy efforts, real improvements in the lives of mentally retarded persons will not occur. Traditional legal services serve them too infrequently, too episodically to alter the agencies which claim to be their "protectors." Class actions exposed patterns of violations of the rights of the "protected," but lacked follow-up capabilities to ensure individual class members a speedy and sufficiently particular remedy. The frustration level of class action lawyers has not been nearly as great as that of lawyers or paralegals confined to service work or lacking the capacity to litigate.

Sustained advocacy pulls together the best of class action and individual representation techniques. It involves not only a time dimension, but the capacity and willingness to concentrate on a focused set of issues for a clearly identifiable population of prospective clients. In this sense, it is the antithesis of the "hired-gun" approach to lawyering. Strategies would not be exclusively court-centered and would treat the client not as an atomized individual, but as a member of a similarly situated client group which suffers discrimination and hardship. Institutions for the retarded (for example) will not be changed, let alone replaced, without a wide array of other monitoring, advocacy and problem-solving methods: new legislation, class actions, individual enforcement actions and meetings with residents, consumer groups and staff interested in the application of new rules. Moreover, clients with long-term needs for care rely, for their very survival, on secure access to a myriad of publicly funded or supervised programs, an access which their lawyers must constantly defend and extend.

Consumer demand for these legal services has spiralled. Where once parents hid their retarded children away, many now insist on the full measure of their children's rights. Where once disabled people were a silent minority, their self-help groups assert claims of entitlement, not charity.496/ Every major legislative or litigative advance has spawned new advocacy opportunities and forums. In the wake of Mills and PARC came P.L. 94-142 and the creation of special education hearing and appeals procedures.497/ In the aftermath of Wyatt came stricter Medicaid MR-ICF certification standards and new state codes on residents' rights.498/ Each step has geometrically expanded the universe of aggressive advocacy possibilities and encouraged consumers to raise their sights.

Advocacy resources have not kept pace with these exceptions. Token projects have been overwhelmed by the transformation of the law on disability rights and its incomplete translation into practice.499/ Moreover, mentally

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496. See, e.g., Representatives of the Handicapped at the White House Conference on Handicapped Individuals for an Alternative Conference Report (available from National Federation of the Blind or White House Conf. on Handicapped Individuals, May 26, 1977). In listing vital advocacy principles, a parent of a severely handicapped child wrote: "That 'equal protection' demands that disabled people be able to use the dollars spent in their 'name' or behalf directly to hire/fire attendants, train attendants, buy or rent a house, purchase services and abode... And, that additionally, the government shall cease and desist from spending as much or more dollar amounts to maintain a person in a setting restricting freedom/community living/good name and status...." Letter from Betty Pieper to author, Jan. 3, 1978.

497. The Education of All Handicapped Children Act of 1975, 42 U.S.C. Sec. 1401, Sec. 1415(b)(d). See also 45 C.F.R. Part 121a 506-510. The Rehabilitation Act of 1973, 29 U.S.C. Sec. 794 and final regulations at 45 C.F.R. Sec. 80.6-80.10 and 45 C.F.R. Parts 81 and 84; and Center for Law and Education, "Children Requiring Special Education: New Federal Requirements," 11 Clearinghouse Review 462-464 (1977).

498. C.F.R. Sec. 449.13 (1977); The Lanterman Developmental Disabilities Services Act, Cal. Health and Safety Code, Sec. 38002 (West Supp. 1977), Ohio Rev. Code Ann. Sec. 5123.94 (Page Supp. 1974).

499. See Herr, Advocacy under the Developmental Disabilities Act 4-7 (1977); Rich, "Special Legal Needs of Residents of Mental Health and Retardation Facilities," (unpublished report, Action Plan for Legal Services, Boston, April 1976).

retarded and other institutionalized people are in no position to compete for neighborhood legal services. In conference after conference, speakers have criticized the lack of a legal services outreach or other tangible commitment to serve this potential clientele. "Of all the identifiable client-groups," Judge Joseph Schneider observed, "the needs of mentally retarded people are among the greatest. In no other area of law has so much changed so quickly."500/ Many conferees shared Judge Schneider's perception that more vocal groups, such as the elderly, prisoners and welfare recipients, had gained the attention of the legal services community. For the mentally handicapped, who are more insular and passive, only a patchwork of legal assistance has been provided.501/

A. Priority Setting

Given the dearth of legal resources for retarded persons, issues of priority setting assume special importance. We know that the mentally disabled fare very poorly in the allocation of legal aid. We face a sharp clash in distribution principles: Shall access to legal services depend on a survival of the fittest, with free legal aid going to the most persistent client or the most vocally aggressive client group? Or are there more equitable principles to ensure that the infirm, the feeble and the confined will have their fair share of the legal services community's attention?

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500. Judge Joseph Schneider, "The Need for a Coordinated Legal Network" (Sept. 29, 1977) (speech delivered to PCMR & NARC Conference on Future of Legal Services for Mentally Retarded Persons).

501. See text and notes at Section III, notes 217-248, and Appendix A; U.S. Dept. of Health, Education and Welfare, Report of Task Group on Deinstitutionalization, Annex 4; Interim Report of the Amici Curiae Work Group 4-42-52 (unpublished report, June 1978); Civil Rights of Institutionalized Persons: Hearings on S. 1393 before the Subcommittee on the Constitution of the Senate Comm. on the Judiciary, 95th Cong., 1st Session 813-14 (1977).

Congress, by law, has now made clear that the latter groups must be taken into account. Under the Legal Services Corporation Act Amendments of 1977,502/ the Corporation shall:

> insure that (i) recipients, consistent with goals established by the Corporation, adopt procedures for determining and implementing priorities for the provision of such assistance, taking into account the relative needs of eligible clients for such assistance (including such outreach, training, and support services as may be necessary), including particularly the needs for service on the part of significant segments of the population of eligible clients with special difficulties of access to legal services or special legal problems (including elderly and handicapped individuals), and (ii) appropriate training and support services are provided in order to provide such assistance to such significant segments of the population of eligible clients;503/

Mentally retarded persons are clearly within the contemplation of the above section 1007 (a)(2)(C). Indeed, it is difficult to imagine a special segment of the eligible client population more appropriate for this special targeting. On grounds of relative needs, the retarded suffer gross economic and social deprivations. Often they lack the barest amenities of decent living. They constitute a "significant segment" of the underserved and unserved legal aid-eligible population, both in terms of numbers and in terms of the consequences of the absence of legal aid.504/ Their special difficulties of access to legal services, as previously discussed, are obvious

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502. Legal Services Corporation Act, P.L. 95-222 of 1977.

503. Id. at Sec. 1007(A)(2)(C).

504. S. Herr, Advocacy Under the Developmental Disabilities Act 5-6, 88 (1976). See also, Presidential Dedication of President Gerald R. Ford, in M. Kindred, et al, The Mentally Retarded Citizen and the Law (1976) at iii. "Only recently have we sought to assure the right of mentally retarded citizens to develop their full potential, to share in the bounty of our land and to receive equal justice under the law."

and incontrovertible. Given their special legal problems, both of substantive law (e.g., commitment, guardianship, institutionalization, etc.) and of procedure (consent, conflicts of interest with fiduciaries), lawyers working in this field desperately need "appropriate training and support services." All the factors that Congress pointed to as impeding access to legal services and requiring outreach capabilities -- lack of mobility, language problems, cultural differences -- may come together in the case of a mentally retarded client. For all these reasons and because they may be unable to champion their own cause, the mentally retarded should be afforded special consideration in priority setting. As recognized by Senate Report No. 95-172:

> To the extent that any identifiable group does have unique legal problems that derive from that identity, . . . the local legal services program should give special attention to such problems in setting its priorities and in making services (available) to particular groups of eligible clients which may be able to be reached only through outreach activities.505/

Setting caseload priorities often turns more on ad hoc than formal determinations. LSC regulations and grant application procedures emphasize local program responsibility for determining priorities and for selecting their own priority setting processes.506/ Other advocacy programs have eclectic methods of caseload management, or no priority setting processes at

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505. S. Rep. No. 95-172, Senate Committee on Human Resources, May 16, 1977 at 13.

506. L.S.C. Regulations, Sec. 1620.2, 41 Fed. Reg. 51609 (Nov. 23, 1976). Memorandum from Charles E. Jones, LSC Director, Office of Field Services to Project Directors, July 28, 1976. For the recommendation that the Corporation define its own program goals and priorities and provide support to recipient programs in identifying both Corporation and local program goals and priorities, see Legal Services Corporation, Report of Task Force on Goals and Priorities, Client Participation and Accountability and Management, in Next Steps for the Legal Services Corporation at 168-69 (April 1978).

all. Whatever the ritual of priority setting, in practice, the advocates' own preferences are probably the most decisive factor. In response to the question, "How does your program determine its caseload management priorities," 24% of the sample referred to staff input, 6% to the personal decision of the attorney and 5% to the project director's determination. Other identified participants were boards of directors (14%), community groups (e.g., advisory councils, public hearings, 7%), clients (10%), and anyone attending the annual project meeting (3%).507/

Many advocates conceptualized priority setting in terms of issues rather than processes. They mentioned impact on other mentally retarded persons, all handicapped persons or other sub-sets of clients (e.g., problems affecting ex-patients, or nursing home residents, or civil commitment respondents, or prospective users of community mental health facilities) as major case selection factors. Others took as the starting point the needs of those clients who presented themselves. Some reported handling all requests for assistance. A number of lawyers focused on the legal techniques they applied (e.g., "affirmative class-wide law reform suits"). Other advocates candidly acknowledged that caseload priorities were products of largely ad hoc factors: crisis responses to client needs, the availability of law students as advocates, ability to schedule client interviews or, what one legal services attorney described as, "the typical bureaucratic position."

In most legal services programs, that position seems not to take into account persons with mental disabilities. Only half of the surveyed advocates state that the mentally disabled were considered in their program's priority setting processes.508/ Program involvement in the mental disability field often turns not on objective measures of client need, but on the availability

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507. Appendix A at 7-8.

508. Id. at 9. The proportion of legal services programs involved in mental disability work is likely to be far lower than indicated by those responding to this survey.

of special funding from outside the Corporation. How do mentally disabled persons come to be taken into account? A handful of special projects, relying on non-LSC grants, concentrate on mental health and/or developmental disability law matters. Other activity is attributable to the special interest or personal choice of a program attorney, to client input, an enabling statute, contact with other advocacy groups or staff input and discussion. Only a few programs referred to client participation or community advisory groups as a source of guidance in this process.509/ Other programs, while marking mental retardation as an area of future activity, have not yet done any specific planning.

Why do programs overlook the mentally disabled in their priority setting? Recalling Freud's observation that we overlook what we do not wish to see, it is understandable that some programs do not perceive a demand for this assistance. Other programs acknowledge the need, but feel unable or unwilling to commit the necessary resources for outreach and legal services. Some advocates erroneously equate legal work for mentally retarded persons with large-scale litigation and do not consider more manageable advocacy efforts.510/ Relegating the mentally disabled to the politics of priority setting prejudices the outcome. Seriously mentally handicapped people have difficulty in speaking for themselves and often lack an organized constituency to support their claims. It is the current, not the potential clientele whose

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509. Id. at 9. Project advisory committees of 5-7 members were formed in Minnesota and Vermont and are in the process of formation in Illinois and Massachusetts.

510. Questionnaire response number 81, staff attorney, Cincinnati Legal Aid Society: "The area was recognized as one we could decide to devote some time to and as one there is some staff interest in. But it has been left out of our recent reorganization because we have been unable to decide if it is important enough to assign the amount of staff to it required to do any significant litigation."

views are sought and who draw up lists of pressing community problems.511/ Without an interested person on staff or some outside pressure, mentally disabled persons will continue to be excluded from legal attention.512/

Advocates should not minimize the role of conscience or their own moral sensibilities in this decision-making. "We got involved in Welsch v Likins," Luther A. Granquist wrote, "because we were so outraged at what we saw. The decision was inevitable to allocate the time."513/ Conditions confronting institutional residents are not deferrable; they often present truly emergency legal matters or, as one attorney bluntly put it, "I start with keeping the shit from being beaten out of them and work my way up from there."514/ Experienced attorneys made clear that the disabled client remains the center of program goal-setting. As Rebecca A. Knittle, former managing attorney of the Minnesota Developmental Disabilities Advocacy Project, emphasized: "Our stated goals are to achieve what the client wants, or in the case of a severely handicapped, non-communicative client, what is in the obvious interest of this client."515/

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511. Current methods of involving clients in the process of priority setting in legal services programs have a predictable bias to the needs of current rather than unserved groups of clients. See, for example, the discussion of "conference" and "survey" methods to obtain the views of clients, Session: "Priority Setting in Legal Services Programs," a session at the NLADA Annual Meeting reported in Legal Services Corporation News (November-December 1977) at 4.

512. As one program candidly replied, they took account of the mentally disabled by excluding them as a class from assistance.

513. Then executive director, Central Minnesota Legal Services and counsel in Welsch v. Likins, 373 F. Supp. 487 (D. Minn. 1974).

514. Questionnaire response of Laurence Gilbert, Director of Research, Legal Aid & Defender Ass'n of Detroit. Another attorney relies on his own priority assessments; "I use my own judgment unencumbered by any restraint except time and my own interest." Questionnaire response of Gabe Kaimowitz at 4.

515. Questionnaire response of Rebecca A. Knittle at 4.

Advocacy for community-based care plainly falls within these obvious interests. So too does challenging harmful institutional conditions and practices. Indeed, advocates listed deinstitutionalization most frequently as a subject matter requiring high priority attention. Institutional conditions and treatment/habilitation issues -- somewhat overlapping categories -- came next. Education, housing and employment, in terms of their importance to mentally retarded persons, were equally ranked. Civil commitment, SSI and other welfare benefits, residents' grievances, guardianship, discrimination in civil rights, correctional/criminal matters and general legal problems were rated next in order. Several advocates viewed access to physical facilities and custody cases as high priority concerns. The legal services attorney in charge of the Mental Patients Advocacy Project at Northampton State Hospital listed confidentiality, competency and organizing residents as future priorities.516/ As far as the retarded are concerned, these issues have received very limited legal attention.

Legal services programs can make issues such as these a major part of their work plans. In Connecticut, Maine, New Hampshire and Western Massachusetts, legal services programs have decided that the rights of institutionalized persons should become their leading priority. An open-ended priorities session and extensive debate, for example, led Western Massachusetts Legal Services to go from voting no resources to voting that all six neighborhood offices spend a major portion of their time on serving mentally disabled, elderly, juvenile and other confined persons as their first

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516. Questionnaire response of Steven J. Schwartz, Managing Attorney, at 9.

priority.517/ Other programs should invite representatives of local and national disability groups or advocacy organizations to their priority setting meetings to provide information and articulate some of the legal needs of low-income retarded persons. Organizations such as legal advocacy or governmental affairs committees of A.R.C.s, or Sec. 113 protection and advocacy systems could have important roles in any priority making process as surrogates for clients who cannot leave institutions or protest denials of rights.

At a case selection level, the following specific issues deserve close consideration: 1) challenges to the necessity for any involuntary commitment on grounds of mental retardation; 2) automatic periodic judicial review of involuntary commitment; 3) creation of a network of less drastic alternatives, including home-based care with domiciliary assistance; 4) access to effective assistance of counsel at all stages of commitment, including treatment and discharge phases; 5) provision of friend-advocates, surrogates under P.L. 94-142, and other forms of lay advocacy in lieu of guardianship or other options restrictive of individual rights; 6) creation, or monitoring of advocacy systems to ensure that independent and vigorous legal advocacy is available to provide direct representation to developmentally disabled persons; 7) state or Federal actions to enforce individual service plans created under Medicaid, P.L. 94-142, or related state laws promoting habilitation in the least restrictive environment; 8) rights to refuse habilitation without retaliatory discharge; 9) damages and injunctive relief to halt abuse and brutality against residents; 10) rights to free habilitation services instead of requiring residents to pay for "tutoring" and other basic habilitation services.

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517. Letter from Steven J. Schwartz to Stanley Herr, June 2, 1978.

B. Resources for Coping with A National Emergency

Recourse to the courts and the legislatures, with all their imperfections and flaws, has brought mentally retarded clients substantial, measurable gains. It has allowed people with disabilities to break out of bureaucratic impasses; to claim rights, not favors.518/ Yet, a host of Federal and state laws - statutory as well as constitutional - have scarcely been tested. Lawyers have especially neglected individual representation and test cases for alleged retarded clients facing civil commitment and other admission procedures.

The positive program of legal advocates in the mental retardation field hinges on the equality norm. This can be illustrated by reference to the so-called "right to education" movement. A substantial line of cases harmonized an egalitarian principle with the demand for special services individualized to students' needs. The logic of Mills and PARC, reducing invidious discrimination and raising public officials' accountability, can apply to other subject matters. The strategy elements are straight-forward: identify a broad-based entitlement, narrow the label leading to segregated settings, eliminate the "no services" option, outline a continuum of less drastic habilitation opportunities, increase the handicapped person's contacts with the non-handicapped and generally raise the costs and procedural burdens of excluding people from community resources. Those principles, first adopted in case law, are now mandated in Federal statutes, providing a carrot and stick to encourage local education agency compliance.

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518. The lead plaintiff in Mills v. Board of Education, (348 F. Supp. 866 (D.D.C. 1972)) for example, has now completed his secondary education. He is reported as having thrived in a private residential school in New York, now lives in a foster home, is starting a job and is no longer regarded as being handicapped. Interview with Scott Surrey, former Junior Village social worker, in Cambridge, Mass. (January 19, 1978).

1. Community Legal Services Programs

Legal services programs can be a decisive resource "in improving opportunities for low-income persons" under the cumulative disabilities of retardation and poverty.519/ Serving such clients is not a new obligation, but the honoring of an old one. Programs can begin by making their offices and staff physically and psychologically accessible to those who cannot simply "walk" into storefront offices, cannot read legal services posters or cannot hear through grapevines of the value of legal aid. Outreach obligations to the handicapped, as the Legal Services Corporation Act Amendments point out, are for the "here and now."520/

Every legal services program should designate one of its staff members a mental disability specialist. Specialization is one of the keys to providing effective legal assistance to an insular minority with unique legal problems. The law and policy making in this area are changing so fast that lawyers engaged in general practice are ill-equipped to handle these cases without substantial support. Larger programs should assign one attorney with primary interest in mental health matters and one in mental retardation/developmental disabilities matters. In smaller programs or offices, the assigned advocate might pursue this work along with a general caseload or a specialized activity in related subject matter fields (e.g., education, juvenile or public benefits law.) While a few attorneys have already carved out such niches, this trend

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519. "Legal Assistance for Residents of Mental Retardation Facilities," Legal Services Corporation News at 1, col. 1 (Sept.- Oct. 1977).

520. P.L. 95-222, Sec. 1007(a)(2)(C); See also Legal Services Corporation, Proposed Instruction Implementing Section 504 of the Rehabilitation Act, 29 U.S.C. 706, 43 F.R. 13927 (April 3, 1978): "A recipient shall conduct its activities so that legal services are readily available to handicapped persons." at 13928.

needs encouragement and official support.[521]

This proposal does not assume a specialist with prior background in this field, only that the nominated advocate be willing to be trained and to keep abreast of current developments. Nor should all cases involving persons with mental disabilities be funneled to the specialist advocate. The ordinary legal problems which mentally disabled people share with others can be handled through general intake, possibly with specialist consultation. At a minimum, the notion of a mental disability specialist ensures that someone can be kept informed of relevant developments, can be mindful of local issues affecting the disabled and can become an in-house advocate in the formulation and implementation of priorities which benefit this segment of the client community. Without some form of staff assignment, can we really expect to pull together outreach, community education activities, cross-referral ties and focused action[522] against institutions which victimize the mentally disabled?

These functions might be best carried out in special advocacy projects for the developmentally or mentally disabled. Special projects have the visibility and legitimacy to attract clients who would not otherwise reach law offices. Since caseload is small at first, such projects have time for outreach and training activities. Mass mailings to consumer organizations, service providers, government agencies and bar groups can announce the project's existence and its services. Projects can also place these announcements in the various newsletters or periodicals which serve the disability community. Project staff can arrange personal meetings with regional mental retardation offices, state and local chapters of associations for retarded citizens, facility directors, ombudsmen, probate courts, human rights committees and others to explain the purposes of advocacy for retarded clients and to develop collaborative ties. Staff, in giving workshops and seminars on retarded persons' rights, can apprise consumers, lay advocates and care providers of emerging areas of rights and appropriate referrals to attorneys.

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[521] Programs in Cleveland, Washington, D.C. and Western Massachusetts already have some specialist advocates in mental disability. The Harvard Center for Law and Education has developed a systematic network of education law specialists through letters, questionnaires and training sessions. Interview with Merle McClung, staff attorney, in Cambridge (Jan. 24, 1978).

[522] Mental health and retardation departments have, by and large, escaped legal scrutiny and focused action. For discussion of features of a "focused legal political action" approach, see Bellow, "Turning Solutions into Problems: The Legal Aid Experience," NLADA Briefcase 106, 121-122 (Aug. 1977).

LSC grantees have spawned pioneering disability law projects, reminders of the aggressive solicitation strategies needed for hard-to-reach client groups. The Illinois Developmental Disabilities Law Project will accept cases attributable to a developmental disability and refer income-eligible clients with other legal problems to general legal services offices. In the Chicago Uptown Legal Services for the Mentally Disabled Project, attorneys regularly visit nursing homes and foster care facilities to protect the rights of ex-mental patients. Through a Vermont Legal Services project, a mailing to every member of the bar produced a pro bono panel of lawyers sharing a developmental disabilities law caseload. These programs have begun to narrow the gap between "law in the books" and "law in action" and to promote a more coherent residential services policy.

2. State Advocacy Systems

Embryonic systems "to protect and advocate the rights of persons with developmental disabilities"[523] can provide spadework for advocacy for persons with mental retardation, epilepsy, cerebral palsy or autism.[524] Under section 113 of the Federal Developmentally Disabled Assistance and Bill of Rights Act of 1975, those systems must have the "authority to pursue legal, administrative, and other appropriate remedies" for eligible clients.[525] As a practical matter, most of those systems are not capitalized, staffed or disposed to assume adversarial advocacy functions. Indeed, most of the agencies now receiving section 113 funds provide no direct legal assistance or only devote small portions of their budgets to that purpose. The very few state systems which have adopted a clear legal advocacy focus are special projects of Legal Services Corporation programs,[526] public defenders[527] or public advocacy offices organized under state legislation[528] or as non-profit corporations.529/

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[523] 42 U.S.C. Sec. 6012 (1977) (P.L. 94-103, s. 113).

[524] See S. Herr, Advocacy under the Developmental Disabilities Act, (U.S. Dept. of Health, Education and Welfare, Developmental Disabilities Office, 1977).

[525] *Supra* note 523. There are no income eligibility restrictions under P.L. 94-103.

[526] These include the Vermont Developmentally Disabled Advocacy Project (Vermont Legal Aid Society) the Minnesota Disabilities P & A System (Central Minnesota Legal Services); Advocates for the Developmentally Disabled (New Orleans Legal Assistance Corporation), and the Delaware P & A System (Community Legal Aid Society). For a full description of the Minnesota program, see Herr, *supra* note 524, at 17-25.

[527] See e.g., Kentucky Office for Public Advocacy, Division for Protection and Advocacy.

[528] For a description of the New Jersey Department of the Public Advocate, (N.J. Stat. Ann. S. 52, 27 E-21 to 27 (1974)), see Herr, *supra* note 52, at 33-40. For other legislatively created agencies authorized to engage in services for some classes of the mentally disabled, see Connecticut Protection and Advocacy System for the Handicapped, Conn. Pub. Act 77-589 (1977); Indiana Protection and Advocacy Service Commission for the Developmentally Disabled, Indiana Code Ch. 19 S.

Section 113 systems need to forge firm linkages to established legal services organizations. One method is for those systems to contract with legal services offices or a state-wide consortium of those offices for the delivery of legal assistance.530/ Another is to develop a referral system to offices whose staffs have special training in developmental disabilities law.531/ Staffs of section 113 agencies will in many instances themselves need training to be more effective advocates or paralegals. Referral can be a two-way street, with section 113 agencies providing counsel for clients over income guidelines, handling cases barred by LSC subject matter restrictions (criminal proceedings, fee generating cases, abortions)532/ or assisting disabled clients with conflicts of interest with other family members. In some instances, section 113 agencies may help with litigation expenses,

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528. Cont'd.
16-13-1 (1977), Mental Health Advocate, Iowa Code Ann. S. 229.19 (1975). (mentally retarded excluded); Maryland Mental Health Information Service, Md. Ann. Code Art. 59, S. 53 (1971); Massachusetts Mental Health Legal Advisors Committee, Mass. Gen. Laws Ann. Ch. 221 S. 34 E (1973); New York Mental Health Information Service, N.Y. Mental Hygiene Law S. 29.09 (1972); North Carolina Advocacy Council for the Mentally Ill and Developmentally Disabled, N.C. Gen. Stats. S. 143B-399 (1977); Mental Health Advocacy Service, LSA-R. S. Sec. 28:64 (West Supp. 1978); Mental Health Advocate, Rhode Island Gen. Laws, 40. 1-5-13 thru 25 (1977).

529. See, e.g., Illinois Developmental Disabilities Advocacy Authority; (New York) Protection and Advocacy System of the Developmentally Disabled.

530. This method has been used in Minnesota (Central Minnesota Legal Services), Illinois (consortium of 5 legal services programs formed for this purpose), West Virginia (Appalachian Research and Defense Fund) and Maryland (Legal Aid Bureau).

531. For example, training programs for legal services lawyers have been co-sponsored by the Florida Legal Services Association and the Florida section 113 system.

532. See Legal Services Corporation Act Amendments of 1977, Sec. 1007(b)(1)-(10).

marshalling data, training, expert witnesses and/or recruitment of pro bono or other co-counsel in major cases.533/ Section 113 agencies and legal services offices can complement, rather than duplicate each other's efforts. Any other action might result in a segregated and inferior network of advocacy offices for the disabled.534/ This would be counter to the very notions of normalization and equal citizenship those offices were meant to promote.

Protection and advocacy systems should supplement, not supplant existing private or public funded advocacy functions. By making the legal profession more aware of the problems of the developmentally disabled, those systems can work to raise the quality and quantity of the representation, particularly in commitment and guardianship proceedings. Section 113 agencies must aggressively employ their authority to reach clients who tend to be inaccessible to other legal services providers. It was the legislative intent that this be "a mechanism by which a developmentally disabled individual within the delivery system has the means to reach outside of the established delivery system for examination of situations in which his rights as an individual citizen may be being violated."535/ Therefore, section 113

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533. Some monies are still available for contracts for direct legal representation. Interview with Suzan Campbell, Director, New Mexico Developmental Disabilities Protection and Advocacy System, in Santa Fe, New Mexico (June 14, 1978) Interview with Jonathan P. Rossman, Director, Florida Governor's Commission on Advocacy for Persons with Developmental Disabilities, in Tampa, Florida (April 1978). Unfortunately, the most common response of state Section 113 plans to legal advocacy needs is simply to refer prospective clients to outside legal services groups and individuals. American Bar Ass'n Comm'n. on the Mentally Disabled, Developmental Disabilities Protection and Advocacy Project: A Review of the State Plans at 7 (April 1978).

534. Segregating the delivery of general legal services on the basis of disability would raise practical and Section 504 objections. Mentally retarded persons need not be shunted off to special projects for general family law, welfare, and housing matters. Specialist work may revolve around status and systemic issues of access to mental disability services.

535. Sen. Rep. 94-160 at 38.

agencies must be able to investigate and monitor alleged violations of rights raised by those individuals and concerned third parties.536/ When those allegations appear well-founded, the agency must be able to file suit for the client or, if the client is incapable of giving consent or is living in an intimidating environment, file in its own name if necessary, or as next friend or guardian ad litem.537/ By screening, investigating and validating complaints, and by taking steps to obtain informal resolutions of valid complaints, the section 113 agency might also forward ripe cases to appropriate legal offices. This may not only represent a more efficient use of scarce resources; it may also combine the advantages of the insider's knowledge of what goes wrong with the outsider's capacity for taking forceful remedial action. While ideally one might wish both assets to be combined in one office, it may prove difficult to sustain both routine and controversial legal services in institution-based projects.538/ By whatever delivery mechanism, section 113 agencies must guarantee the isolated or the severely handicapped client the promise of a day in court or in any other forum in which speedy remedies can be obtained.

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536. See generally, American Bar Ass'n. Comm'n. on the Mentally Disabled, Advocacy for Developmentally Disabled Persons 26-28 (Discussion ed. Jan. 1978); Mass. Gen. Laws Ann. Ch. 221 Sec. 34E (1973) (Mental Health Legal Advisors Comm. may provide legal assistance on third party referral to persons unable to make assistance requests).

537. See, e.g., Barbara C., through her best friends, The Ohio Legal Rights Service v. Moritz C 2-77-887 (S.D. Ohio E.D. Nov. 17, 1977). The Ohio Legal Rights Service is authorized under Ohio Rev. Code Sec. 5123.94 to represent developmentally disabled individuals. See other cases cited at notes 478-83, supra.

538. Dickey & Remington, "Legal Assistance for Institutionalized Persons: An Overlooked Need," 1976 So. Ill U.L.J.175 (1976).

3. Consumer Organizations

Client-oriented advocates and consumer organizations should form symbiotic relationships. In the wake of court or legislative victories, someone must monitor the results. If consumer organizations will not, who will?[539] In the face of sharp divisions in the handicapped community, someone must reconcile the competing legal and policy choices. If client-oriented advocates will not, who will? Litigation, legislation or proposed administrative reforms, properly framed, can become an organizing tool for consumer groups. When the American Coalition for Citizens with Disabilities brought suit to force the HEW Secretary to promulgate Section 504 regulations and brought direct political pressure to bear through demonstrations and sit-ins, it made the issuance of Section 504 regulations a victory for disabled people themselves. When New York consumer groups brought Federal suit and sustained a five year campaign to replace the world's largest mental retardation institution with a network of group homes and halfway houses, it reversed a whole set of priorities in the Department of Mental Hygiene. When individual residents, their parents and the Pennsylvania Association for Retarded Citizens won their case against the Pennhurst State School as a segregated and discriminatory facility, they placed state officials around the country on notice that institutions should be dismantled, not repainted. In each of these cases, teams of advocates kept loose coalitions hinged together, responded to the real anxieties of consumer organizations that crude remedies would lead to state dumping of residents and provided a legal presence to speed reform. Around the country, lawyers have helped to empower consumer organizations, to give them added clout at bargaining tables by making litigation a credible prospect and to remind consumers of the many appropriate uses of the law to reduce patterns of discrimination and "rightlessness." The Transbus agreements and the recent Vermont developmental disabilities legislation are but two of the varied examples of this.540/ There is every good reason for advocates and consumer groups to be patient with each other and to strengthen their alliances.

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[539] The Massachusetts Association for Retarded Citizens, for example, is training lay members to inspect the community residential facilities into which state school residents are being transferred. Interview with Peter Lincow, Executive Director, in Cambridge (Oct. 1977). The Michigan Association for Retarded Citizens, by bringing two lawsuits on abuse of institutional residents, has triggered a wide variety of legislative responses and the resignation of the Director of the Michigan Department of Mental Health. Memoranda from Harvey D. Zuckerberg, Executive Director, (March 1, & 7, 1978).

There are new voices which must be added to the dialogue on the future of legal advocacy efforts in this field. Lawyers can aid mentally retarded people to form their own groups and organizations. How many sheltered workshops for the disabled have any form of labor organization? How many institutions or group homes permit any form of self-government for their residents? How many community-based programs ask the consumers whether their rights are respected or how the program can be improved?541/ How many human rights committees have consumers as members?542/ The short answer is "not

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540. See note 408 supra. In Florida, the threat of litigation was sufficient to prevent the construction of segregated 100 bed institutions for the retarded. Interview with Linden Thorn, Executive Director, Florida Ass'n. for Retarded Citizens, in Madison, Wisconsin (July 21, 1978).

541. Gan, Tymchuk & Nishihara, "Mildly Retarded Adults: Their Attitudes toward Retardation," 15 Mental Retardation 5 (Oct. 1977) ("Without contribution from retarded people, professionals, parents, or educators of the retarded will continue in a manner which may be prejudiced, paternalistic, or authoritative in forming decisions about the life and needs of others.")

542. For the requirements that a resident of a mental retardation facility be included in its human rights committee, see Wyatt v. Stickney, 344 F. Supp. 387, 407 (M.D. Ala. 1972). At the Fernald State School, a resident had been a member of the Human Rights Committee. Although the individual was still living at Fernald and although the superintendent recognized that a resident could and should join the Committee, no action was taken to solicit a resident's participation. Interview with John Gracie, Superintendent, Fernald State School in Waverly, Mass. (Feb. 1, 1978).

very many." That answer is likely to be true whether the unit serves those termed mentally ill, or mentally retarded, or physically impaired, or others segregated on the basis of disability or alleged disability. Some individuals may have neither the interest nor the aptitude to be drawn into these forms of participation. The risk, however, is that service providers will peg expectations for client participation at levels of the lowest functioning, not at the levels at which the clients are capable of participating.543/ In Massachusetts, for example, a self-help group of young mentally retarded adults, called the Mohawks and Squaws, have staged conferences, consulted with service providers and given newspaper interviews in order to protest the paternalism and prejudices which impede them.544/ There are other groups of people calling themselves retarded in this country and in Europe who are demanding respectful treatment and recognize themselves as a new minority. A whole new movement for people with disabilities shares that consciousness and demands civil rights protections. That movement is symbolized by the agenda

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543. The lumping together of people with a wide variety of disabilities in mental retardation and developmental disabilities programs often results in treating mentally competent persons as incompetents. See B. Bechdol, "Competent Consumers in a Stew," in Proceedings of the Illinois Conference on Advocacy and the Developmentally Disabled 171 (Jan. 21, 22, 1977). "...the competent consumer in the D.D. stew has rarely been asked, even more rarely heeded, about his need and goals." See e.g., Karst, Foreword: "Equal Citizenship Under the Fourteenth Amendment," 91 Harv. L. Rev. 1, 68 (1977) "the principle of equal citizenship insists that such people (the victims of stigma and nonparticipation, including those with serious physical or mental handicap) be offered community membership, not that they accept it; it is no violation of the principle for a black in Montgomery to choose to sit in the back of the bus."

544. For the past 11 years, this organization has provided some 150 consultations to human service agencies on mental retardation issues and generally addressed matters of discrimination and overprotection. Members prefer to refer to themselves as mentally retarded citizens and see themselves as part of a new minority. Personal observation of a consultation meeting of the Mohawks and Squaws, at Lesley College, in Cambridge (May 1, 1978).

and alternative agenda produced at the White House Conference for the Handicapped, recommending inter alia, more vigorous legal attacks on discrimination against the handicapped and the institutionalized handicapped.545/ The message of that conference, like that of the Mohawks and Squaws, is that disabled persons themselves are the real experts on disability and must be treated as people worthy of respect, people to be consulted on the legal issues that matter to them.

In recent years, such organizations of retarded persons have begun to speak out for their own interests and to counter stereotypes of retarded persons as unable to make personal choices. Medicaid ICF-MR regulations now encourage self-government for interested residents.546/ Advocates can assist and support self-help groups and help bring resident self-government into being.547/

Legal services staff can work with these consumer groups in numerous ways. As volunteers, they can join their boards, legal advocacy committees and advisory panels. As attorneys, they can represent low-income members and their organizations asserting the rights of similarly situated disabled persons. They can encourage voter participation by retarded persons and can

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545. Alternative Report of the White House Conference on Handicapped Individuals at 4 (May 27, 1977, available from the White House Conference on Handicapped Individuals, 1832 M. St., N.W., Washington, D.C. 20036).

546. 45 C.F.R. 29.13(b)(1)(ix).

547. Murky institutional policy can impede resident self-government. See, e.g., Walter E. Fernald State School, Policies and Procedures Manual 150 (July 1, 1977): "Where practicable and desired by interested residents, there shall be a form of self-government developed and voted upon at Fernald School, which may address aspects of a small or large portion of their daily living routines." While residents have expressed interest in such self-government, they have had no assistance in drafting the self-government plans which, by this policy, must first be submitted to the superintendent for his approval.

assist in removing discriminatory legal barriers to voting, especially for those in institutions. In Kentucky, Washington State, Michigan, Minnesota and elsewhere, legal services attorneys have represented State Associations for Retarded Citizens in class actions for institutional residents. As counselors to self-help groups, they can advise those groups of their rights to organize and to participate in the governance of the social agencies created for their benefit. For example, under Sec. 504 regulations, consumer groups have the right to be a part of agency audits of Sec. 504 compliance. Imagine the institutional superintendent confronted by residents demanding those Sec. 504 rights: that scenario, however, will not occur without close legal liaison to disabled consumers and their groups. To a far greater extent than previously realized, retarded citizens can be trained to vote, recognize and comprehend their rights,548/ to testify as to agency compliance with basic human rights549/ and to acquire some self-advocacy skills.550/

4. Legal Services Corporation

The Legal Services Corporation has the power to support and encourage legal assistance efforts for the indigent mentally retarded. National conferences have urged the Corporation to get "closer to the needs of retarded

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548. In California institutions, simple drawings depicting residents' rights are posted on walls, and some residents are trained to understand 10 basic residents' rights. Personal observation at Fairview State Hospital, June 16, 1978.

549. O'Donnell, "Residents Rights Interview," Mental Retardation (Dec. 1976). Institutional residents have also testified in major cases such as Pennhurst, supra; Willowbrook, supra; Townsend v. Treadway. No. 6500 (M.D. Tenn. 1973) and Brown v. Ristich 36 N.Y. 2d 191, 366 N.Y.S. 2d 124 (Ct. of App. 1976).

550. Chan, Brophy & Mar, Developmental Disabilities Advocacy Project: Final Report (U. of Wisconsin School of Education, Feb. 1976); Herr, "Rights Into Action," 26 Cath. U. L. Rev. 203, 209, 304 (1977).

citizens," citizens suffering "(g)ross infringements upon human rights . . . on a day to day basis."551/ Prominent judges have proposed increased initiatives to protect the rights of the mentally disabled and the institutionalized.552/ Judge Joseph Schneider, a member of the American Bar Association's Commission on the Mentally Disabled, has even observed that it would be "ironical for the Corporation to be sued by the mentally handicapped

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551. "A Conference on the Future of Legal Services for Retarded Persons: The Airlie House Report," September 1977 (Co-sponsored by the National Association for Retarded Citizens and the President's Committee on Mental Retardation, at 3, 11 (1977). The National Association for Retarded Citizens (NARC), the leading consumer organization with some 300,000 members, on July 22, 1978 adopted the following resolution:

> WHEREAS mentally retarded persons are among the chronically underserved poor persons and in many cases are unable themselves to seek legal assistance,
>
> THEREFORE BE IT RESOLVED THAT the NARC Executive Committee vigorously urge the National Legal Services Corporation, and its local programs to extend and strengthen their advocacy efforts in behalf of retarded persons, both in the community and in institutional residential facilities.

552. Flaschner, "Legal Rights of the Mentally Handicapped: A Judge's View," 60 A.B.A. J. 1371, 1374 (1974). Bazelon, "Institutionalization, Deinstitutionalization & The Adversary Process," 75 Col. L. Rev. 897 (1975). Circuit Judge Shirley M. Hufstedler, "Remarks for the Long-Winded" (speech to Institute for Judicial Administration, in Chicago, Aug. 6, 1977) at 8:

> "The conditions in many of these institutions are not merely inhumane, they are downright inhuman. The inmates are our most helpless citizens. They have no political voice. Our society does not even like to acknowledge that the inmates exist -- a sentiment that, if not shared, is at least readily perceived by legislators. At the present time, about the only way in which the plight of the confined is revealed and pressure is brought to improve them is through lawsuits."

for their fair share of legal services."553/ With virtual unanimity, questionnaire respondents feel the Legal Services Corporation and local programs can and should do more in this area of legal assistance.554/ Even with its decentralized structure, there are, as the following pages show, a number of constructive options for the Corporation.

Local programs need considerable help from the Legal Services Corporation to represent mentally retarded persons effectively. Resource materials, training sessions, consultation services, information exchange and special funds are only a few of the identified needs. These efforts must concentrate on stimulating local interest and assisting local offices to be advocates for the mentally disabled on an ongoing basis. A specialist back-up center, or regional centers are proven methods for accomplishing aims of this kind. Questionnaire results placed back-up centers as the top-ranked form of needed outside assistance in providing legal advocacy for mentally retarded persons. A good center, which respects the sensibilities of local advocates and their clients, can be a mechanism for delivering a wide variety of assistance and can pull many fragmented efforts together.

There are now thirteen LSC funded back-up centers, termed "National Legal Services Specialized Litigation and Support Centers." Some are

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553. Joseph Schneider, Cook County Circuit Court Judge, "The Need for a Coordinated Legal Network," (remarks presented to the National Conference on the Future of Legal Services for Mentally Retarded Persons, Airlie House, Virginia, Sept. 29, 1977).

554. Sixty-three out of sixty-five advocates concurred in this response. Questionnaire response, number 66, at 10. Appendix A at 30. One way for local programs to learn about the legal needs of retarded persons and begin to meet those needs is to invite organizations, such as Associations for Retarded Persons, to priority setting sessions. Their proxy input for potential retarded clients who can not attend those meetings is especially needed, since some families who have institutionalized children may be reluctant to raise these issues. Interview with Charles E. Jones, LSC Office of Field Services in Washington, D.C. (Aug. 24, 1977).

organized around subject-matter topics (welfare, education, employment), while others deal with segments of the client community (migrant workers, Indians, juveniles, the elderly). Mental disability legal assistance involves both distinctive service delivery agencies and distinctive classes of stigmatized poor persons. Haphazard events, not rational planning, account for the distribution of national support centers. It is difficult, for example, to fathom the logic by which juveniles had, until recently, two LSC-supported back-up centers, while the mentally disabled - with equally vexing problems of access to legal services - have none. The 1977 amendments to the Legal Services Corporation Act, with its mandate to reach the handicapped, and repeal of the so-called Green amendment restrictions on back-up centers555/ pose the perfect opportunity to rectify this historical oversight.

The reasons for doing so should already be apparent. Training, technical assistance and clearinghouse functions can now be recombined in national support centers with direct client legal assistance. The 300 local legal services programs require these and other forms of aid in a new, complex and rapidly changing field of law affecting the poor. Advocates entering this field will need substantial and ongoing training, and the counsel of lawyers and other professionals experienced in working with mentally disabled or alleged disabled clients. That training and counsel is not readily available to the approximately 3,200 full-time attorneys and 1,200 paralegal assistants in local programs. Moreover, their needs go well beyond mere schooling in the

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555. The Green Amendment, Section 1006(a)(3), authorized the Corporation "to undertake directly and not by grant or contract", various research, training and clearinghouse activities. See H.R. Rep. No. 95-310, 95th Cong., 1st Sess. (1977), and So. Rep. 95-172, 95th Congress 9-10 (1977). For indications of interest in identifying new substantive areas, see A. Houseman & J. Riggs, Support needs and Options: A Discussion Document 34-38 (unpublished, Legal Services Corporation, July 1978).

kaleidoscope of Federal, state and local rules of substance and procedures. While Program Support can have a joint role in sponsoring training conferences, local programs need more than one-shot outside assistance to handle retardation cases. Through a back-up center, other forms of essential outside assistance can be organized: consultation, intensive training, developing a pool of expert witnesses, drafting model documents, providing co-counsel, of counsel and amicus assistance and doing countless mundane tasks. The availability of that assistance on a regular basis can make the difference between success or failure for a given client, between coherence or fragmentation in strategies to help such clients nation-wide. The few public interest law offices involved in this area have neither the staff nor the funding to engage in the full range of support activities. As an American Bar Association lawyer aptly expressed it, "we are only able to do this on a piecemeal approach -- we are not able to provide either the quantity or quality of assistance offered by (LSC) back-up centers."556/

Resource materials on mental retardation and the law are still extremely limited. The advocates surveyed for this study ranked this as the second most needed form of outside assistance, and overall mentioned it most frequently. It is easy to see why. Beyond a handful of law review articles, a few broad books and a scant number of manuals, the area remains largely unexplored and uncharted by legal writers.557/ Even this limited literature is rapidly becoming outdated under the explosion of new legislation, regulations and

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556. Interview with Joseph Varygas, Director, American Bar Association, Mental Disability Legal Resource Center in Washington, D.C. (Jan. 17, 1978).

557. See, e.g., R. Knittle (ed.), Legal Rights of Developmentally Disabled Citizens: An Advocacy Manual for Minnesota (1977); American Association on Mental Deficiency, Consent Handbook (Special Publication No. 3, Task Force of the AAMD Legislative and Social Issues Committee, 1977); P. Friedman, The Rights of Mentally Retarded Persons (1976).

court decisions. Needed materials include handbooks on communication with, and consent from retarded clients; starting institutional legal services projects; representing retarded persons before human rights committees; state and national manuals on developmental disabilities laws generally, and SSI, ICF-MR, Medicaid and civil commitment of the retarded (and its abolition). The considerable volume of unpublished opinions, brochures, public policy statements, cognate social and behavioral science literature - inaccessible to most practitioners - makes the production of resource materials a strenuous and vital task.

Training programs are sorely lacking. Particularly in the newer advocacy programs for the developmentally disabled, it is more a matter of blind luck than planning that advocates receive special training. The situation in ordinary legal services offices is even worse. Attorneys and lay advocates alike must be able to attend seminars, conferences and training sessions geared to the specific and recurrent problems of the mentally disabled client.558/ They may need help, too, with problems of communicating and feeling comfortable with their clients; their own instincts to paternalism, avoidance of the unattractive client, deference to professional caretakers and a host of ethical dilemmas that are as complex as any faced today in the practice of poverty law. Training seminars have to date, rarely come to grips with learning the bare bones of new law, let alone the nuances of this practice. One exception was a recent two-day training conference, jointly sponsored by Florida Legal Services, Inc. and the Florida section 113

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558. The bulk of this training should be held at a state level. Advanced training on Federal programs, such as Section 504, Medicaid, SSI, the Developmental Disabilities Act or Federal institution litigation could perhaps be better conducted at national or regional meetings. See generally, Statsky, "Paralegal Advocacy Before Administrative Agencies: A Training Format," 4 Toledo L. Rev. 439 (1973).

advocacy system. It brought together some 60 lawyers, representatives of legal services programs and public defender offices, for sessions on the law, community placement and non-discrimination aspects of representing developmentally disabled persons. The Florida example is especially timely because Congress has permitted the Corporation to provide grants to local programs for statewide or regional training.559/ Through Program Support and state resource center units, the Corporation can provide similar introductory, as well as advanced training programs at state and regional levels. Even more intensive training institutes - perhaps in conjunction with outstanding legal services projects in this field - will be needed for attorneys intending to specialize in developmental disabilities or other mental handicap work.

Novice and experienced attorneys alike need a range of consultation services. They need the advice of people who have not only litigative or legislative skills, but expertise in a host of programmatic matters. The topics are as diverse as they are important: what constitutes an adequate habilitation plan, what alternatives are there to heavy psychotropic medication, what are the vocational training capacities of severely retarded persons. These are but a few of the technical issues advocates may face. Advocates also need a clear and readily available source for outside review of pleadings, critiques of proposed remedies and assessments of the replicability of tactics which were successful in other jurisdictions.560/ Hard-earned lessons must be better shared from case to case and from state to state.

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559. S. Rep. 95-172, 95th Cong., 1st Sess. 9 (1977); H.R. Rep. 95-310, 95th Cong., 1st Sess., 8 (1977).

560. The Justice Department's Special Litigation Section may be able to provide limited consultation assistance on cases within their area of expertise, particularly Federal right to treatment and least restrictive alternative suits. Remarks of Karen Christensen at ABA Commission on Mentally Disabled Advocacy Projects meeting, Washington, D.C. (December 16, 1977).

Information exchange among advocacy projects for the mentally disabled is haphazard. Lawyers working in the field report a sense of isolation and a hunger for information regarding how their colleagues elsewhere handle similar practice situations. These often inexperienced advocates have no other lawyer in their office, program or vicinity who can be a role model or adviser in their mental disability work. Consequently, they can easily become disheartened while attempting to cope with an unfamiliar and psychologically taxing field. Clearinghouse functions should go beyond dissemination of legislative bills or impact litigation papers to a broader exchange of materials: brochures to clients and consumer groups,[561] access agreements relating to confined clients, reports of successful and/or imaginatively handled service-cases, training materials, case studies of fruitful non-litigative strategies. Here again is a function that the proposed national or regional back-up centers could perform. In the interim, the National Clearinghouse Review could create a special developmental disabilities section allowing for inclusion of a wider-range of documents as described above. Encouraging lawyers to produce and share those documents can help offset the distorting view that only "big cases" lead to visibility and recognition. Retrieving these work products is also a way to counter some of the loss of information and expertise which accompanies staff turnover.

National legal services planning does not adequately take into account the needs of the mentally retarded and other institutionalized or disabled populations. In its first decade, there was an understandable preoccupation with service delivery involving mainstream legal aid problems. Minimum access to legal services is currently defined by the Corporation, as the equivalent of two attorneys per 10,000 poor people.562/ This formula assumes that in a given year only one in three of the poor will have a legal problem, and that far fewer will actually seek legal assistance. The inadequacy of a base budget which annually allots $7.00 per poor person for legal services is patent enough. Applying that calculation to the legal needs of a resident of a mental retardation institution is just absurd. Carfare to interview a client in a remote facility could consume that total by itself. Plainly, any legal aid funding formula must be realistically adjusted for programs serving institutionalized or other hard-to-reach mentally retarded people.563/ That readjustment would consider the additional costs imposed by outreach, distance, staffing needs, project start-up and the novel socio-legal problems encountered by the client group.

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[561] See, e.g., Legal Services for the Mentally Disabled of Uptown, The Rights of Residents of Nursing Homes (pamphlet 1977).

The Legal Services Corporation should establish cooperative working relationships with H.E.W. in order to plan, support and coordinate access to legal assistance for developmentally disabled persons. If formal and informal ties can be developed at national, state and local levels, it should be possible to maximize the capacity of LSC funded legal services programs and HEW funded section 113 agencies to provide that legal advocacy. The interagency agreement between the Corporation and the Administration on Aging of the Department of Health, Education and Welfare provides a prototype for such

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562. Legal Services Corporation, Annual Report at 14. If the Corporation reaches its announced goal by 1979, its budget will rise to between $275 and $300 million dollars. The ratio of lawyers to the general population is approximately 14 lawyers for every 10,000 persons. Weaver, "Legal Services Now Thrives on Success, Not Controversy," The New York Times, July 31, 1977 at 4E, Col. 1.

563. Interview with Linda Potter in Seattle, Washington (Jan. 2, 1978). Ms. Potter described the impossibility of attempting to "cover" five institutions, spread across the state, for the mentally retarded and the sense of helplessness in trying to assist 3,500 residents with only one attorney and a paralegal.

a relationship. Those agreements, reached in 1977, set an agenda for increasing the number of communities with legal services for the elderly.564/ Two LSC employees are assigned to HEW to ensure that the agreement is properly implemented. Similar arrangements for the retarded and other developmentally disabled persons are needed; to increase resources, improve access to existing back-up centers, foster joint training activities, and to bring into being these specialist legal services in all parts of the country.

New advocacy programs - whether publicly or privately funded - should learn from the lessons underlying the Legal Services Corporation. They must insist upon insulation from political pressures and upon client-oriented advocacy free from funding-source control within the terms of the Code of Professional Responsibility. The lessons of creating and sustaining a system of full and independent advocacy need to be more fully shared. The rationale for a liaison between the Corporation and HEW to assist the developmentally disabled is precisely analogous to that employed in establishing such a relationship to assist the elderly.565/

Mentally retarded people are among the chronic losers in the great legal

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564. Statement of Understanding between the Administration of Aging, Department of Health, Education and Welfare and the Legal Services Corporation, signed in Washington, D.C. on January 18, 1977.

565. The LSC-HEW agreement states that:

> The need for legal services among persons who are elderly is becoming increasingly apparent. While older persons have the same legal problems as any other age group -- housing and consumer matters, for example -- they also have unique problems associated with their age, such as decrimination in employment, pensions, nursing homes and home health care, an increasing reliance on public benefits. In addition, the relative lack of mobility of many older persons often causes difficulty in gaining access to legal services, even when they are available. Id. at 1.

aid sweepstakes. They will likely remain so until the Corporation directs some specific resources to the retarded poor. Funding is obviously a common denominator in implementing the recommendations set out in these pages. Even if the Corporation budget were to double again, this would be no assurance that more mentally disabled clients would receive effective legal assistance. Unlike other groups, the retarded are often least aware or comprehending of their rights and least able to secure legal services or to advocate for themselves. As the preceding sections of this book make clear, they have truly a singular and sorry legal history.

Affirmative steps are needed to improve disabled persons' access to existing legal services and to increase the programs' capacity and willingness to serve them. Legal services money should be specifically allocated for this purpose. Congress has earmarked generic services funds for the handicapped in the past. The Headstart program, for example, is required to allot no less than 10% of enrollment opportunities for handicapped children.[566] Legal services, like public education, has had long-standing policies that resulted in serious underservice of the handicapped. But whereas school administrators

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566. 42 U.S.C. Section 2928b(d) (1977 Supp.):

> the secretary shall establish policies and procedures designed to assure that... not less than 10 per centum of the total number of enrollment opportunities in Headstart programs in the Nation shall be available for handicapped children and that no less than 10 per centum of the total number of enrollment opportunities in Headstart programs in each State shall be available for handicapped children... and that services shall be provided to meet their special needs.

For other special mandates to allot funds to serve the handicapped in generic programs, see 42 U.S.C. Sec. 4953(a)(2) (1977) (assignment of VISTA volunteers to work with mentally ill, developmentally disabled and other handicapped individuals, especially those with severe handicaps); 42 U.S.C. Sec. 1438 (1976 Supp.) (low-income housing projects to handicapped persons).

no longer excuse this underservice, in legal services circles it is still commonly said: "We will serve the disabled (or retarded, or mentally disabled) if special funding is available." That logic was not acceptable from the mouths of school boards and principals; it sounds no better from legal services boards and attorneys.567/

The Legal Services Corporation is empowered to set goals that would grant the handicapped their share of legal aid assistance. Affirmative action can open up local, state and national programs to the mentally handicapped poor. Not only can goals be set, but the Corporation can make supplemental or incentive grants to programs proposing substantial projects to serve this group with special difficulties of access. Alternatively, it could dedicate a certain portion of each program's grant to redressing the needs of the handicapped, a dedication deferrable only if the program could demonstrate a present inability to use those funds or some other compelling need for redirection. Many programs would welcome a goal, especially if accompanied by new money to carry out Corporation directions to make legal services fully accessible to the handicapped. Without stronger incentives from national and regional offices, local programs are unlikely to tackle the problems of a client-group whose needs require greater outreach and patience than normal. Moreover, the Corporation and the National Legal Aid and Defender Association

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567. See, e.g., Mills v. Board of Education, 344 F. Supp. 866, 875-876 (D.D.C. 1972). The separate opinion of Justice Blackmun, referring to affirmative action for handicapped persons and others is especially apposite:

> In order to get beyond racism, we must first
> take account of race. There is no other way.
> And in order to treat some persons equally,
> we must treat them differently.

Univ. of California Regents v. Bakke, No. 76-811 (Sep. Op. at 5, June 28, 1978).

should recognize and commend individual attorneys who render significant and pioneering service to these clients.568/

5. The Bar and the Law Schools

Representing the mentally disabled is more than a legal aid problem. Four out of five questionnaire respondents believe that the legal profession and Bar groups generally can and should do more in this area of legal assistance. Those who dissent feel that, while more work is needed, it is unrealistic to rely on the fee-for-service private Bar to perform it. The American Bar Association recognizes the society's and the legal profession's chronic neglect of the mentally ill and the mentally retarded, and has pledged corrective steps.569/ Despite efforts to mobilize the profession to share this concern, only limited progress has been made. Although mental disability affects all economic strata, the burden of representing the more seriously disabled falls unevenly on legal services and public interest lawyers.570/ Private lawyers simply do not see indigent retarded clients in typical practices.571/ Yet, as one neighborhood legal services attorney recognized,

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568. An annual award, perhaps presented at the NLADA Annual Meeting, would not only recognize past accomplishment, but also bring to the attention of the legal services community the acute vulnerabilities and injustices which persons with mental retardation suffer. Interview with E. Clinton Bamberger, Jr., L.S.C. Executive Vice President, in Washington, D.C. (Aug. 24, 1977).

569. American Bar Association, Policy Resolutions Adopted at 1975 and 1977 Annual Meetings, Reprinted at 1 Mental Disability L. Reptr. 506 (1977).

570. ABA Commission on the Mentally Disabled (in cooperation with the Mental Health Association), Legal Advocacy Programs for the Mentally Disabled: A Preliminary Survey and Directory (Feb. 1977).

571. Private attorneys do not compete for these clients, and hence are likely to be supportive of free legal services for the mentally disabled. As expressed by Thomas Ehrlich, Legal Services Corporation President, "In the beginning all the shopkeepers and landlords and lawyers were afraid of us. The lawyers thought we would steal their

the organized profession has support roles to play: "I believe the Bar should work towards creating an experienced mental health bar through training and special funding, otherwise the mentally disabled will remain under-represented as well as often poorly represented."572/

The options for Bar support are many. Private lawyers can donate money and raise funds for special projects. Where the cases are major, they and their firms sometimes assist in pro bono litigation.573/ In a few states, referral panels have begun to operate to assist clients with routine legal matters.574/ Conferences in Oregon and Massachusetts have acquainted members of the Bar with legal representation needs of retarded and other developmentally disabled persons. Other states, through continuing education programs, have raised awareness among practicing lawyers and judges of those distinctive needs. Bar organizations, through endorsement of and lobbying for

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571. Cont'd.
clients, but the people we help would never have gone to a private lawyer anyway. Now the bar associations realize this." Weaver, "Legal Services Now Thrive on Success, Not Controversy," The New York Times, July 31, 1977, at 4E col. 2. See generally, Champagne, "Lawyers and Government Funded Legal Services," 21 Villanova L. Rev. 860 (1975).

572. Questionnaire response of Richard Cole, Staff Attorney, Greater Boston Legal Services, at 11.

573. See, e.g., Maryland Association for Retarded Citizens v. Maryland, Equity No. 100/182/77676 (Cir. Ct. Baltimore Cty., April 9, 1974) (Statewide right to education decree obtained by NLADA staff attorneys and pro bono counsel from three large Baltimore and Washington law firms). Letter from Daniel Walker to author (plans to provide pro bono assistance to persons with epilepsy) (August 3, 1978). Interview with Charlotte Keller, Staff Attorney, Neighborhood Legal Services in Washington, D.C. (March 27, 1978). ($17,000 grant from D.C. Bar Association will enable legal services office to hire an attorney for physical and mental handicap issues).

574. In Vermont, for example, the State Bar Association sent a mailing to all attorneys, inviting their participation in a developmental disabilities legal panel. To date, legal services attorneys report a strong response from private attorneys, particularly in referrals concerning special education. Interview with Neil Mickenberg, in Washington, D.C. (Dec. 17, 1977).

legislative, regulatory or administrative reforms, can lend their prestige to reform objectives.[575]

If law schools scarcely prepare their graduates for aiding "rational" clients, they certainly don't prepare them for presumptively "irrational" ones. While the "reasonable man" and the corporate entity hold the center stage of curricular attention, problems of mental disability barely creep into the wings. If dealt with at all, the subject may be introduced in terms of the insanity defense or psychiatry's mystique - topics affecting only miniscule numbers of potential clients. The student is left with scant comprehension of mental retardation, the key roles of attendants in residents' lives, or indeed, most aspects of the institutionalization process. Clinical law programs integrated with classroom presentations are a partial antidote to these distorted images of mental disability law and treatment. A few law schools have begun to develop such clinical placements, introducing students to a world in which clients are not uniformly attractive, articulate and well-organized, and helping students to be more comfortable with clients that most lawyers shun.[576]

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575. American Bar Association Commission on the Mentally Disabled, Directory of Bar Mental Disability Committees (October 1977) (although all the committees are not currently active, the Directory lists committees in 35 state bar associations and 59 county or city bar associations).

576. Those law schools include Harvard (mental retardation facilities), Yale (mental hospital), University of Maryland (developmental disabilities), University of Toledo (mental health) and Ohio State (civil commitment).

For a description of using law students to expand legal services available to drug addicts, see Velman & Eldridge, "Providing Legal Services to the Addict: An Experimental Law School Clinical Program," 4 Contemporary Drug Problems 3 (1977).

Legal services programs and the profession as a whole clearly have a stake in making clinical legal education more readily available.577/ Attracting young lawyers who will enter and remain in mental disability and other poverty law areas may depend on those law school experiences. Many leading practitioners were first introduced to low-income clients through internships, part-time jobs and clinical placements in their law school years. Mental disability law projects often report that law student performance is better than private lawyer performance. In some of those offices, law students have major responsibilities in intake, investigation, research and other client-assistance functions. Given direct supervision from law school staff, law students working with developmentally disabled clients can make substantial service contributions.

6. Executive Responses to the "Mental Retardation Crisis"

From the Federal government through state departments of mental health, there is a rhetoric of change without the substance of change. From time to time, a proposal surfaces for a Marshall Plan for those in institutions.

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576. Cont'd.

To encourage more law school clinical programs to provide training and opportunities for representing retarded persons, the NARC has adopted a program of awarding certificates of commendation to students completing such a clinical program.

577. See Ehrlich, "To Serve the Poor: Law Schools Must Provide a New Set of Skills," Learning and the Law, 37, 41 (Spring 1977):

> "We believe legal aid clinics that provide direct legal assistance to poor people could be developed at more schools and, to the extent those clinics do serve the poor, some support might be possible from the Corporation."

Nothing happens. Periodically, the President voices a national goal of movement toward community-based care, or campaign promises of equal rights for "our handicapped citizens."578/ Little follow-up results. State departments of mental health with increasing frequency report huge numbers of people unnecessarily restricted; for example, a fourth of New York's 26,000 adult mental hospital patients are found not ill enough to be hospitalized.579/ For years to come, they will stay confined.

The carrots and the sticks that would free them and produce alternatives to institutions are missing. In fact, we may be "had" by all the talk of "community resources", "integration," "normalization" and "deinstitutionalization" of the mentally disabled. The mental retardation division of the New York State Department of Mental Hygiene, allocated a budget of $235,000,000, one year earmarked only $2,000,000 for community programs.580/ Government agencies expend $2.8 billion annually for some

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578. 1976 Democratic Presidential Campaign Committee, Jimmy Carter on Americans with Disabilities: "As President, I will take all necessary steps, through specific legislation and appropriate exercise of executive powers, to insure our handicapped citizens equal protection under the law, equal opportunity for education, employment, and other services, and equal access to public accommodations and facilities."

Remarks of the President to the White House Conference on Handicapped Individuals, in Washington, D.C. (May 23, 1977):

> When I was inaugurated Governor of Georgia in January, 1971, I made a speech and I said in that Southern State the time for racial discrimination is over, and I say to you tonight the time for discrimination against the handicapped in the United States is over.

579. Weisman, "28% Are Held in Mental Hospitals Needlessly, New York Study Finds," The New York Times, at A1, col. 1 (January 15, 1978).

580. Blatt, "The Executive," in The President's Committee on Mental Retardation, Changing Patterns in Residential Services for the Mentally Retarded (Rev. Ed. 1976) at 150.

2,800,000 retarded children and youths.581/ What does it buy? New York State, with a half billion dollar institutional building program in mental retardation, took the Syracuse State School with a resident population of 250 and rebuilt, on the same segregated site, a new state school for 750 residents at a cost of $25,000,000.582/ Around the country, similar rebuilding and modernization is taking place, locking future generations behind freshly painted walls.

There are public officials in Departments of Mental Hygiene who have forgotten their agencies' missions. Mindful of every interest group, they subordinate the interests of their mentally retarded clients. There are attorneys within those departments more solicitous of the sensibilities of experimenters than of the well-being of helpless departmental clients.583/ There are officials who know of institutional staff who abuse residents or neglect their rights but are unable to discharge them.584/ There are institutional doctors of marginal competence who would first sterilize residents before discharging them.585/ To all this and more, most local prosecutors and law enforcement agencies have turned an essentially blind eye. In Los Angeles, the prosecutor's office has been an exception, refusing to recommend

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581. J. Kakalik, et al., Services for Handicapped Youth: A Program Overview 2, 13 (Rand Corp. 1973).

582. Blatt, supra note 580, at 135.

583. Interview with Michelle White, formerly Monitor of the Massachusetts mental retardation state school decrees, in Boston (Nov. 3, 1977).

584. See, e.g., New York State Senate Select Committee on Mental and Physical Handicap, Violence Revisited: A Report on Traditional Indifference in State Mental Institutions Towards Assaultive Activity 27-30 (1976).

585. See, e.g., Wyatt v. Aderholt, 368 F. Supp. 1382 (M.D. Ala. 1974).

civil commitments of respondents to uncertified state mental retardation institutions, but this barely curbs state lawlessness.586/ We do indeed need better ways of holding professionals in this field accountable for their actions.

In these circumstances, judicial intervention can only intensify. Until mental retardation budgets redirect larger shares for community services, large institutions will be prominent targets for major law suits. Increasingly, those suits should probe the liability of individual defendants for their actions.587/ Advocacy efforts of all kinds must attempt to pinpoint individual responsibility for callous or incompetent handling of mentally retarded clients. The "mental disability system" may be the origin of such evils, but this provides no blanket absolution for individual wrong doing or complacency. Officials and professionals have known for decades of the harm caused by large segregated setting and have had time to prepare alternative plans. Scientific findings showed that throwing increased staff into custodial environments did not necessarily improve care or result in more interaction between attendants and residents.588/ Yet, state planners and HEW have funneled Medicaid mental retardation and other funding primarily into institutional care. There are superintendents and admitting physicians and

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586. Interview with David Guthman, Deputy Prosecutor, Los Angeles County, in Los Angeles, California (January 6, 1978).

587. See, e.g., Rogers v. Okin, C.A. No. 75-1610 (D. Mass. April 30, 1975), aff'd No. 77-1201 (1st Cir. Dec. 8, 1978) (order restraining forcible medications in non-emergencies). "Retarded Girl's Care Denounced in Court," The New York Times, Jan. 12, 1978 at 39, col. 1 (seven Boston State Hospital plaintiffs locked in seclusion and forced to take drugs against their will seeking $1.2 million in damages, including a retarded girl secluded for 106 hours over a five day period).

588. Grant & Moores, "Resident Characteristics and Staff Behavior in Two Hospitals for Mentally Retarded Adults," 82 American J. of Mental Deficiency 259, 263 (1977).

staffs who knew this and more, but instead told anxious parents that their children required life-long care inside institutional walls. Under these terrible legacies of misinformation and rationalization, the institutions now flounder.

There are mental retardation specialists and officials who have broken with the frozen ideologies and institutions of the past. They deserve applause, support and emulation. David Rosen, for example, now director of Macomb-Oakland Regional Center, was for many years a superintendent of mental retardation institutions. In only four years, the Regional Center, a state agency of the Michigan Department of Mental Health, placed over 650 clients from large state institutions back into their home communities through family-care training homes, group homes and apartments. Geared to returning mentally disabled persons to the community, MORC develops settings and support services most appropriate to their clients' needs, provides periodic follow-up, pays family-care house parents to do specific selected training programs with clients and offers continuing social work and health services to those residents in homes. Instead of taking the paucity of community placements as a given, the Center created 20 group homes and over 100 community training homes (which serve one or two clients each). While superintendents around the country are catching brickbats and court complaints, Rosen is catching bouquets. Both the Comptroller General of the United States and the Michigan Legislature have commended the Regional Center as operating one of the best mental disability programs in the nation.589/ In human terms, clients once

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589. Michigan Legislature, Senate Concurrent Resolution No. 50 (A Concurrent Resolution Honoring the Macomb-Oakland Regional Center). For description of the Macomb Center and other community alternatives, see MacDonald, "Varieties of Residential Alternatives," 5 Innovations 23, 31-32 (Spring 1978) (published by American Institutes for Research in collaboration with National Institute of Mental Health).

regarded as hopeless and profoundly retarded are now learning new skills and living in ways which show the erroneousness of earlier institution-based assessments. There are successful programs in Nebraska and elsewhere which have recorded similar findings. Why, then, haven't programs of this kind been replicated around the nation? Legal services attorneys representing institutionalized clients should be citing these examples in their briefs and asking such questions before courts and legislatures.

7. Congress and the State Legislatures: New Champions for the Disabled?

State and Federal governments must not abdicate their basic responsibilities to save handicapped people from debilitating institutionalization: it should not be left to the vagaries of litigation in the 50 states to settle this nation-wide problem. A Congress that gave the handicapped Section 504, 94-142, and 94-103 cannot be indifferent to current violations of constitutional rights and disincentives that impede the creation of community-based alternative care facilities. By establishing reliable funding-streams for community care and client advocacy, Congress can spare this generation and future generations of residents and their families the hurt and guilt of institutionalization. What fills institutions like Willowbrook and Pennhurst and Partlow is coercion and the absence of other choices. Such institutions are products of an outdated philosophy propped up in brick and mortar and social insecurity.

Congress has, in recent years, taken seriously the rights of mentally retarded and other disabled persons. A number of state legislatures have similarly awakened to these issues.[590] Lest inertia and bureaucratic timidity nullify recent legal gains, our legislatures must recognize and accept the work remaining to make good the promises of equal respect and concern for the disabled. The problem of residential services for the retarded demonstrates a conspicuous neglect of those promises. It will neither go away nor be resolved by executive or judicial tinkering. Were Congress to give the problem of mega-institutions the same attention as school exclusions, similar progress would be made. Were state legislatures to look as kindly on the disabled as they do on the elderly,591/ Willowbrooks and Rosewoods would not be tolerated.

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[590] For an account of Montana's experience, see Marbut, "The Legislature," in P.C.M.R., Changing Patterns in Residential Services for the Mentally Retarded, 119 (1976). New community-oriented legislation in Vermont, Florida, California and Minnesota is reviewed in text and notes, at notes 408-412, supra.

Deinstitutionalization needs a better vehicle than the Medicaid or the Developmental Disabilities Assistance programs. The former is now a force for shoring up institutions, while the latter is a comparatively low-budget attempt to exhort the states to do better. The very concept of "deinstitutionalization," as reflected in those statutes, needs a new label and a more positive thrust. P.L. 94-103, for example, requires that 30% of the states' formula grant monies be reserved for "developing and implementing plans designed to eliminate inappropriate placements in institutions for persons with developmental disabilities."592/ This is a very murky and backhand way of creating more community-based programs and services. If the states "eliminate" institutional placements, what placements and services will they provide instead? In the light of recent case law, for whom is segregated institutional care not "inappropriate?" Medicaid provisions on intermediate

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591. Referring to support for elderly programs, Barney Frank, a State Representative in Massachusetts said, "if socialism ever comes to America, it will come in a wheelchair." "'Gray Power' Emerging as a Strong Political Force," The New York Times, November 28, 1977, at 26 col. 1. While the mentally handicapped may elicit the same sympathy as the elderly, they lack the potent political power.

592. 42 U.S.C. Sec. 6062(a)(4) (1977). See also 42 U.S.C. Sec. 6063(b)(20).

care facilities for the mentally retarded do not resolve these difficulties, only compound them. As long as Federal reimbursement monies bear the major costs of institutional care, but almost none of the costs of less restrictive care in community settings, deinstitutionalization predictably muddles along. Deinstitutionalization turns into a slogan rather than a coherent program when the states fail to reallocate funds, currently spent on institutions, for community care, "an obvious rebudgeting," which, in the understated words of a Congressional committee, "has not always occurred in conjunction with deinstitutionalization efforts."593/

Congress needs to create a substantial formula grant program for states organizing community-based services to replace institutions. Those services should be available not only for current institutional residents but also for those living at home or in out-of-home settings. As a condition of participation, states could be required to submit plans for the phasing-down of mental retardation institutions and the creation of specific networks of alternative living and support services. Those services include group homes, specialized foster care, halfway houses, homemaker and home health services and other designated community-based diagnostic, treatment or habilitative services. Equally important, those plans should stress home-based services, including programs and subsidies for parents, adoptive or foster parents and other family members caring for mentally retarded persons at home. Examples of this assistance are respite care, subsidy payments for the extra costs

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593. U.S. House of Representatives, Report on Developmental Disabilities Legislation, P.L. 94-103, H.R. No. 94-58 (1975) at 10. At present, local governments have financial incentives to send off to state institutions disabled persons who could be better served nearer their homes. State as well as Federal laws clearly express policies of least restrictive alternatives for mentally retarded persons. The policies are made meaningless, however, by the executive's failure to redirect resources and staff to an embryonic community-based residential care sector.

accompanying home care and access to specialist counselling, social work and health services.

An act for the "Community Reintegration of the Mentally Disabled" could apply to the current and prospective residents of both mental hospitals and retardation institutions. In addition to a deinstitutionalization incentive formula grant tied to a specific federally approved community reintegration plan, the states would provide matching monies specifically targeted to meeting these disabled persons' housing, residential supervision, independent living, vocational and related rehabilitational needs. These services would be based on a developmental rather than a medical model; accordingly, they would emphasize residential settings for 8 or fewer clients and would be in facilities which have waivers from inappropriate medical model Life Safety Code and other Medicaid requirements. As a further legislative recommendation, Congress should halt costly and counterproductive capital improvements of state mental institutions, making approved deinstitutionalization plans an alternative means of compliance with Title XIX. Eliminating the arbitrary one-third reductions of SSI grants for persons living in the household of a relative or receiving charitable subsidies would also encourage community reintegration of the mentally disabled.594/

States can not both pour open-ended resources into segregated institutions and start rival community-based facilities on the scale required. New Federal funds could provide the critically missing "up-front" monies

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594. Additional recommendations are set out in U.S. Department of Health, Education and Welfare, Office for Planning and Evaluation, Task Force on Deinstitutionalization: Annexes 1-10 (June 1978). H.E.W. undermines its own credibility in promoting community-based care in the states by its persistent failure to redirect funds from St. Elizabeths Hospital toward deinstitutionalization. Indeed, the Administration proposes to spend an additional $50,000,000 next year to upgrade buildings and care at the Hospital.

needed to establish community-based residential and support services. States which failed to submit plans or whose plans did not meet these requirements would find their allotment transferred to public or private agencies or organizations developing community alternatives.

This "Community-Based Service" legislative proposal could effectuate constitutional principles now sorely ignored. Its adoption could avoid institution-by-institution litigation, suits carrying the risk of inconsistent standards and long delays in obtaining remedy. Judicial decision-making is not a comprehensive process. Furthermore, adequate supervision of institutions under court order is time-consuming and incomplete. Moreover, state defendants faced with litigation in one institution may be tempted to strip other institutions of resources. Without substantial increases in the stock of community residential placements, states will be tempted to reserve most group homes for those now on the rolls of state mental retardation institutions. The result of this rationing, as in Massachusetts, is the unhappy spectacle of one group of underserved disabled persons being pitted against another.

Instead of a decade-long struggle to enforce ICF-MR standards in debilitating settings, "community-based service" plans could call for deinstitutionalization and redirection in institutional budgets. Plans such as those designed by the Macomb-Oakland Regional Center can provide for the evacuation of institutions with careful attention to meeting residents' post-transfer needs. Given assured funding and continuity of care in community settings, the genuine fears of parents' groups could be allayed and wider political support obtained. As in recent education for the handicapped laws, retarded citizens must not be denied options for fuller lives while administrators wait for the courts of the 50 states and the territories to rule. Here, to an even greater extent than with the Juvenile Justice and Delinquency Prevention Act,595/ national legislation is essential "to provide critically needed alternatives to institutionalization."596/

Monitoring and advocacy are basic tools for implementing this national policy. Congress, in renewing the Developmental Disabilities Act, can strengthen the capabilities of advocates to defend the rights of those who receive, or seek habilitation services.597/ Appropriations for the protection and advocacy systems, currently limping on meager rations, should be multiplied several times. Section 42 U.S.C. Sec. 6010, pertaining to the rights of developmentally disabled persons, should be recast as declarations rather than Congressional findings.598/

Any "deinstitutionalization" or "community reintegration" legislative package should include specific authority for legal services and other forms of client-directed advocacy. Without such advocacy to reduce institutionalization and promote and monitor the provision of community-based services, accountability and human rights for mentally disabled persons will remain

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595. 42 U.S.C. Sections 5601-5751 (1977).

596. 42 U.S.C. Section 5602(b)(2) (1977).

597. Developmentally Disabled Assistance and Bill of Rights Act, 42 U.S.C. Sections 6001-6068 (1977). Public Law 95-602, Sec. 508 (U.S. Code Service 1978) provides for increasing protection and advocacy authorizations, now at $3 million, to between $9-15 million.

598. 42 U.S.C. Section 6010(1), for example, finds that "Persons with developmental disabilities have a right to appropriate treatment, services, and habilitation for such disabilities." The administration has moved to delete this section in its entirety, a direction which would seriously weaken the civil rights thrust of developmental disabilities legislation. For proposed legislation which would retain the current "rights" provisions and would increase the funding of protection and advocacy systems from $3 million to $9 million for fiscal year 1979, see Consortium Concerned with the Developmentally Disabled, "Proposed Language for the Renewal of the Developmental Disabilities Act Now Known As P.L. 94-103" (1977, available from United Cerebral Palsy Associations, Inc.).

slogans. Comprehensive legal services should be available on a group and individual basis to mentally disabled persons in institutions and in the community through two basic types of mechanisms. Statewide projects would focus on individual legal representation, legislative and regulatory reform and provide leadership in enhancing advocacy resources to enable clients to live independently in the community. Institution or catchment area-based projects would be responsible for meeting the legal needs of, and monitoring the responsiveness of service systems to clients in defined geographical regions.599/ Projects would equitably divide their attentions between mentally retarded and mentally ill populations, possibly with separate administrative subdivisions. On a national level, this advocacy program might be administered by the Legal Services Corporation, with some collaboration from HEW and with proposals for projects solicited from all types of legal services providers. For a more orderly development, projects could be phased-in over a two or three year period, some 17 to 25 states per year. These advocacy programs would thereby be independent of the mental disability service delivery system, be able to pursue their clients' full range of formal and informal remedies and be able to involve clients in program design and train them as lay advocates for themselves and others. Without clearly authorized public funds for these purposes, retarded and mentally ill persons will not have their pressing advocacy needs met.

Legislation assuring the Justice Department statutory authority to pursue those rights is imperative. Bills before the last Congress would have

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599. Advocacy programs organized around catchment areas could provide continuity of legal assistance for a defined population of persons who may shift between institutional, group care and independent living situations. Where mental disability services were concentrated in large institutions, legal advocacy projects could devote the greatest proportion of their time to assisting institutional clients and pressing for community-based options.

permitted the Department to bring suit or to intervene against state and local institutions which deprive residents of rights secured by the Constitution and laws of the United States.600/ Participation of the United States in these suits lends vitally needed investigative resources, credibility and expertise. Recent decisions that the Department lacks standing to sue without enabling legislation imperils this continued contribution.601/ Current bills would provide the missing express authority to sue where there is "a pattern or practice of resistance to the full enjoyment" of the institutionalized person's constitutional and statutory rights. Congress, in the past, has granted the Attorney General similar authority to protect the Federal rights of persons subject to widespread deprivations of civil rights.602/ It should do so here, for people in mental institutions, facilities for the handicapped, nursing homes and other institutions, are people on the frontier of civil rights legislation.

In several suits, the Justice Department has played an effective role in protecting the rights of endangered retarded inmates. No other legal advocacy organization has the current resources to pursue constitutional litigation for the institutionalized on a truly national scale. Moreover, effective representation of institutionalized retarded clients requires that the lessons

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600. S. 1393, as amended, 95th Congress, 1st Sess., reported out of the Subcommittee on the Constitution, November 15, 1977, by a vote of 4-0, with the recommendation that it be acted upon favorably by the Committee on the Jidicary. These have been reintroduced, in a more restrictive form, as S.10 and H.10.

601. United States v. Soloman, 419 F. Supp. 358 (D. Md. 1976), aff'd 563 F. 2d 1121 (4th Cir. Oct. 12, 1977); United States v. Mattson, C.A. No. 74-138, 46 L.W. 2241 (11-15-77) (D. Mont. 1977).

602. See e.g., Civil Rights Acts of 1960, Title VI (voting); Civil Rights Acts of 1964, Tits. II & VII (public accomodations and employment discrimination); Civil Rights Act of 1968, Tit. VIII (housing); State and Local Fiscal Assistance Act of 1972 (discrimination in programs receiving Federal assistance).

of one case be carried directly into the next. In matters of Federal law, expert evidence, investigative resources and monitoring techniques, the Civil Rights Division's Special Litigation Section can help provide this continuity.

The presence of Justice Department lawyers is a necessary, but not a sufficient step toward adequate legal assistance for institutional residents. Leading cases have often been the products of teams of local attorneys, public-interest law specialists and Civil Rights Division attorneys.603/ This not only ensures the fuller factual and legal development of multi-faceted cases, but keeps vital issues from being overlooked. While the Justice Department has largely focused on the vindication of Federal constitutional rights, the plaintiffs' legal services and other local attorneys have raised Federal and state statutory claims. Moreover, attorneys for mentally disabled inmates sometimes bring claims against the Federal Government which the Justice Department might find awkward or impossible to assert.604/ Local attorneys who are more familiar with local conditions and their plaintiffs' desires, may be better able to take flexible and innovative approaches. Passage of the Justice Department is standing legislation would, therefore, be a tool for more effective legal services work in this field, not a grounds for local program abdication.

The failure of the Justice Department to raise violations of Federal grant programs illustrates the point. Had the United States chosen to enforce the condition of a grant intended to benefit retarded residents or sought relief for breach of a contract pursuant to which such a grant was made, the standing decision of the United States Court of Appeals for the Fourth Circuit

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603. See, e.g., Wyatt, Willowbrook, Pennhurst cases.

604. See, e.g., Dixon v. Weinberger, 405 F. Supp. 974 (D.D.C. 1974); Caswell v. Califano, 77-0488-CV-W-4 (W.D. Mo., July 29, 1977).

might have been otherwise.605/ The evidence in that case showed that over a two year period Rosewood State Hospital received over $14 million in Federal grants designed to aid mentally retarded residents. As Circuit Judge Butzner observed,

> To secure these funds the state was required to comply with the constitutional provisions, laws, and regulations governing their disbursal. If the government had brought suit to enforce the conditions of the grants or for breach of contract, quite a different question might well have been presented. It has long been recognized that the United States has implied authority to sue for vindication of its proprietary and contractual interests in grants that it has made.606/

That observation goes far beyond an issue of standing to the very integrity of Federal assistance programs. A full range of advocacy services is required for the mentally disabled lest human rights promises remain hollow declarations. The Developmental Disabilities Act, for example, requires that state plans contain assurances that "the human rights of all persons with developmental disabilities (especially those without familial protection)" in assisted programs will be protected.607/ Though there have been many instances of human rights violations, no state has ever had its plan disapproved for failure to comply with human rights assurances. A more flexible range of incentives and sanctions is needed in lieu of the current all or nothing approach. Something must lie between the rusty powers of funding cut-off or continued receipt of funds by non-conforming states. If

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605. U.S. v. Solomon, 563 F.2d 1121 (4th Cir. 1977).

606. Id. at 1129 (concurring opinion). See U.S. v. County School Board of Prince George County 221 F. Supp. 93, 103 (E.D. Va. 1963) (educational impact funds); United States v. Frazier, 297 F. Supp. 319, 322-24 (M.D. Ala. 1968), 317 F. Supp. 1079, 1082-84 (M.D. Ala. 1970) (grant in aid programs).

607. 42 U.S.C. Section 6063(b)(24) (1977).

Congress will not articulate intermediate options, the courts may be called upon to devise appropriate remedial orders which salvage Federal funds for their intended purpose.[608]

There is a real danger that mental disability professionals and public officials will regard laws conferring rights to retarded persons as no more than aspirational statements or unenforceable declarations of principle. With scant training in understanding the requirements of law, institutional staff, in particular, may easily develop a cynical disregard of residents' rights. Frequently, staff who view themselves as residents' advocates are penalized, while those adopting passive and even negative stances toward residents' rights are indirectly rewarded. Legal and other forms of external advocacy must counterbalance the inertia and complacency which insular institutions engender.

Long-term solutions lie with states and local communities and with a fundamental policy change to no longer abandon the retarded and their families to institutional "last resorts." New state legislation can forcefully redirect preferences toward community care and restructure mental disability departments and resources to accomplish those preferences.609/ As in Rhode Island, states can promote deinstitutionalization by enacting laws which subsidize home care for mentally retarded persons.610/ The error of past public policy has been to confront the families of retarded persons with a bleak choice: put the child into an institution for life-time care at public expense, or shoulder the burdens of care with little or no outside support or financial assistance. The abolition of large institutions will not come until something better stands in their place and until parents are no longer faced with this Hobson's choice. That will require comprehensive and integrated community living arrangements and services, including family support services, domiciliary assistance with personal aides and attendants, respite care, foster care, subsidized adoption611/ and group-living options. State legislation can also reduce the overly broad labelling of the retarded, place

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[608] See, e.g., Mattie T. v. Holladay, C.A. No. DC-75-31-S (N.D. Miss. filed April 25, 1975); Bond v. Stanton, 372 F. Supp. 872, (N.D. Ind. 1974), aff'd. 504 F.2d 1246 (7th Cir. 1974), cert. denied 420 U.S. 984 (1975) (reduction of Federal payments is not sole remedy; declaratory and injunctive relief available to individuals directly affected by non-conforming state plan). See also, Karst, Foreword: "Equal Citizenship Under the Fourteenth Amendment," 91 Harv. L. Rev. 1, 24-25 (1977). When the burden of legislation falls most heavily on a group that is likely to be the subject of the legislature's systematic neglect, it is natural for judicial scrutiny to be heightened.

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609. See, for example, Florida Ch. 77-335 (June 24, 1977); Colorado Rev. Stat. 27-10.5 (Supp. 1976); Kentucky Rev. Stat. Ann. Section 202B.040 and Section 202A.210; Louisiana Stat. Ann. 28:50(2) (West. Supp. 1978); Michigan Stat. Ann. Section 14.800 et seq.); Nebraska (L.B. 806 April 6, 1976); Ohio Rev. Code Sections 5123.67 et seq.); Pennsylvania (50 P.S. Section 7101 et seq.); Rhode Island Ch. 23-43.1-21.1 (August 1977) and Virginia Code Sections 37.1-63 et seq.); Wisc. Stat. Ann. Section 55.02 (West Supp. 1976).

610. 1977 R.I. Pub. Laws, Ch. 23-43.1-21.1 (August 1977) Termed the "Parent Deinstitutionalization Subsidy Aid Program", it provides payments to natural, adoptive or foster parents found qualified to take into their care a retarded person thereby removed from a state institution. Continued payments are for basic care and for training, and are in addition to any basic payments provided foster parents. The program, in operation for less than a year, has so far resulted in seven persons placed in home care. Interview with Joseph Bevilacqua, Director, Rhode Island Department of Mental Health, Retardation and Hospitals, in Washington, D.C. (July 20, 1978).

611. Subsidized adoptions are provided for in at least forty-six states. This trend recognizes that fiscal encouragement is necessary in order to move hard-to-place children out of temporary, albeit long-term, living situations and into a permanent home. Children with physical or mental disabilities are special targets for public financial subsidy. The National Association of Attorneys General, Legal Issues in Foster Care (Comm. on the Office of Attorney General, Feb. 1976) at 37-40. See Model State Subsidized Adoption Act, (Prof. Sanford N. Katz, Boston

the handicapped within the purview of anti-discrimination laws, bar exclusionary zoning of group homes and provide compensatory assistance to undo barriers to generic services. All these steps, and more, are needed if mentally retarded people are no longer to be America's untouchables.

C. Conclusion

Equal access to justice means more than having law offices open in theory to mentally retarded persons. It is more than a matter of filing writs or waiting passively for disabled clients to appear. The principle of equal citizenship forbids the organized society to treat an individual "either as a member of an inferior or dependent caste or as a nonparticipant."612/ Securing that principle of equal concern and respect cannot be left to the pro bono efforts of private lawyers or the sporadic intervention of the legal services bar. Joyce Murdock has told us why this is not enough. Involuntarily sterilized at age 14, while a resident of a state mental retardation institution, she remained there for nearly six years because she had no advocate or legal representative to turn to for help in getting a

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611. Cont'd.
College Law School, project director, funded by DHEW, Children's Bureau). See also N.C. Gen. Stat. Section 48-39 (Supp. 1975), which covers the mentally handicapped and seeks to encourage "the adoption of certain hard-to-place children in order to make it possible for children living in, or likely to be placed in foster homes or institutions, to benefit from the stability and security of permanent homes...." National legislation has also been proposed for adoption subsidies for handicapped and other institutionalized children who now lose Federal assistance if removed to adoptive homes. Rosenbaum, "White House Backs Subsidy for Adopting Unwanted Children," The New York Times, July 9, 1977 at A1, col. 4.

612. Karst, supra note 608, 91 Harv. L. Rev. 1, 6 (1977): The principle of equal citizenship presumptively insists that the organized society treat each individual as a person, one who is worthy of respect, one who "belongs."

foster home.613/ Her own statement best conveys how far Congress and we have yet to go:

> I feel that all the retardeds like me that just has a reading problem and are a little slow learning should be out in the world because this is their world too, and, we don't want to be treated no different or people to feel sorry for us. But we don't want to be knocked around just because we're born this way. . .
>
> We don't like to have to be sterilized and not be able to have a family and have marriage life just like you or your wife and family or like any other family, because, we are normal, and we got feelings. But people really just looks at us and says we are retarded and all this and says she can't do this and she wouldn't know how to do that. But they really don't trust us or give us a chance to show what we really know.614/

The problems of Joyce Murdock and those more disabled than she are neither unique nor transitory. They should remind us that the distinction between legal and social problems is at best artificial. Efforts to resolve problems of the retarded are not a legal fad; neither will a great legislative advance or a landmark judicial opinion sweep away the ills of their stigma and degradation. After institutional horrors are redressed, there will be other equally pressing calls from retarded persons for the legal profession's attention. The severely disabled will not vanish nor will the vulnerabilities that mark their powerlessness and lack of militancy.

As long as the supply of trained advocates remains so small, the doors to courthouses, legislatures and agencies are barred to mentally retarded persons. While the legal services community has made a promising beginning,

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613. Testimony of Joyce Murdock, former resident of Caswell Center for the Mentally Retarded, United States Senate, Subcommittee on the Constitution, Hearings on Civil Rights of Institutionalized Persons, (95th Cong., 1st Sess., 1977) at 94, 96-7.

614. Id. at 99.

the gap between advocacy needs and advocacy resources is shockingly wide. The preceding recommendations - among them special funding, back-up centers and specialist attorneys and projects in local communities - would increase the staying power and skills of advocates interested in these underserved clients. "All we would like," Joyce Murdock wrote for herself and other retarded persons, is "to have the opportunity for you to help us get opportunity by helping us get rights and not feeling sorry for us and anything."615/ Until affirmative steps are taken to answer that request, the mild, patient and sometimes hidden people we call retarded will be destroyed in countless ways.

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615. Id.

APPENDIX A

Questionnaire Results

LEGAL ADVOCACY FOR MENTALLY RETARDED PERSONS

APPENDIX A A-1

QUESTIONNAIRE: LEGAL ADVOCACY FOR MENTALLY RETARDED PERSONS

I. IDENTIFICATION

Name ______________________ Position ______________

Program ______________________________________

Mailing Address _______________________________

1- 2 City __________________ State __________ Zip ________

Telephone ( ) ___________________________________
Area code

II. INTEREST AND EXPERIENCE

3- 4 Total years of experience in legal service/legal advocacy: ___

5- 6 Years of experience in legal advocacy for retarded persons: ___

Type of experience: (Please specify years in each type)

7- 8 ____________________ Neighborhood Office

9-10 ____________________ Law Reform Unit

11-12 ____________________ Public Interest

13-14 ____________________ Private Practice

15-18 ____________________ Other (Please specify)

19-21 Number of attorneys in current program: ______________

22-23 Number of other advocacy in current program: ______________

Area served by Program:

24 ____________________ City/County/or other geographic unit
(specify which)

25 ____________________ Primarily urban/or rural
(specify which)

26-29 ____________________ Overall population (est.)

II. INTEREST AND EXPERIENCE

3-4 Total years of experience in legal services/legal advocacy: ____________________

No experience	2
Under 1 Year	8
1 Year - Under 3 Years	19
3 Years - Under 5 Years	17
5 Years - Under 10 years	39
10 Years or Over	11

5-6 Years of experience in legal advocacy for retarded persons: ____________________

No experience	17
Under 1 Year	8
1 Year - Under 3 Years	17
3 Years - Under 5 Years	11
5 Years or Over	20

7-8 Type of experience

Neighborhood Office 43

Years Worked	# People
Under 1	1
Under 2	4
Under 3	4
Under 4	7
Under 5	3
5 - Under 10	7
10 and Over	1
No response for Years	16
	43

9-10 Law Reform Unit 28

Years Worked	# People
Under 1	
Under 2	7
Under 3	4
Under 4	3
Under 5	1
5 - Under 10	3
10 and Over	1
No response	9
	28

11-12 Public Interest 17

Years Worked	# People
Under 1	1
Under 2	4
Under 3	3
Under 4	1
Under 5	2
5 - Under 10	1
10 and Over	1
No response	4
	17

13-14 Private Practice 13

Years Worked	# People
Under 1	1
Under 2	2
Under 3	-
Under 4	2
Under 5	-
5 and Under 10	3
10 and Over	1
No response	4
	13

Other 47
No response (1 no response was a judge) 6

15-18 Other	Years of Experience
Hospital	
University Advocacy Center	
Consumer Advocacy	
Community Volunteer	
Protection & Advocacy Service	
Court assigned civil committee cases/defense work	
Association for Retarded	24
Handicapped Persons Legal Support Unit	
Juvenile Defense Unit	1
Private Defender's Office (as student)	1
Advocate - training and law reform	1
Administration	2
Government & law professor	
Judicial clerkships	2
Law Student clerkship	1
National Employment Law Project, Inc.	
Legal services at a state mental hospital	
Bank trust department	5
State Department of Mental Health	5
Law school - clinical	2
Center for Law & Health Services	
Law School Clinic-Yale	
National Child Advocacy	4
Specialized Mass. Litigation Practice	
Public defender	
Law clerk to California Sup. Court	3.5
National Juvenile Law Center	
Staff attorney-U.S. Commission on Civil Rights	5
Reginald Heber Smith Fellow	2
Mental Health Legal Services	7
Cook County Legal Assistance Found., Inc.	
"private practice" but contractually special counsel to the mentally ill	
Legislative drafting	2
State Supreme Ct. clerk	
Legal service clinical program	
Administrative	2.5
State agency	3
National Center for Law and the Handicapped	
Health Law Project (U. of Pa.)	
VISTA	
State legal protection service	
Institution	
Special Unit Legal Services Program	
NY State Legal Protection Service	2
LSP Support Center	2.5
New Orleans Legal Assistance Corp.	
New Orleans Legal Assistance Corp.	
Government	
Elderly project	
State agency designated to represent mentally retarded and mentally ill	

Juvenile Unit	
Mental Hospital MH Unit	
Central Office - Orient state institution (Columbus Legal Aid)	
ACLU Exec. Dir.	
Developmental Disabilities Training Institute	
Association for Retarded Citizens	3
Mass. Dept. of Mental Health-Div. of Mental Retardation	
Justice Department	
Public Defender's Office	3

19-21 Number of attorneys in current program: ________________

0	3
1-4	29
5-9	18
10-24	18
25 or more	21

22-23 Number of other advocates in current program: __________

0	9
1-4	25
5-9	10
10-24	16
25 and over	5

24 Area served by program:

________________________ City/County/or other geographic unit (specify which)

City	9
County	32
Multi-county	13
State	29
Multi-state	1
National	8

Other

Neighborhood	1
Reservation	2

25 __________________________ Primarily urban/or rural (specify which)

Urban	48
Rural	10
Mixed (urban & rural)	12
Suburban	2

26-29 ______________________________ Overall population (est.)

Under 100,000	7
100,000 - 249,999	5
250,000 - 499,999	12
500,000 - 999,999	15
1 million - 1,999,999	14
2 million - 2,999,999	3
3 million - 3,999,999	6
4 million - 4,999,999	1
Over 5 million	6
National	4

30 Are there mental retardation residential facilities in the area covered by your organization?

Yes 84 (Name of facility, if known) ____

No 7 Don't Know 5

31 Have you ever represented clients with retarded mental development?

Yes 75 No 13 Not sure 6

32 .... clients with other developmental disabilities?

Yes 72 No 15 Not sure 8

33 ..... clients with physical disabilities?

Yes 72 No 14 Not sure 6

34 If so, please specify ____

III. LEGAL ADVOCACY

35-36 What percentage of your time is devoted to advocacy for a) the legal rights of mentally retarded persons?

37-38 b) all mentally disabled persons?

39-40 c) all disabled persons?

% of Time

	0%	1-24%	25-49%	50+%
a)	19	33	11	16
b)	13	22	8	28
c)	9	31	8	17

41 How does your program determine its caseload management priorities? ____

42 Did that priority setting process take into account persons with mental disabilities? Yes 53 No 13

43 How? ____

44 If not, why not? ____

45 Have you advised, or spoken before, organizations of, or for mentally retarded or other disabled persons?
Yes 68 No 25

46 If not, would you be willing to do so? Yes 33 No 4
Possibly 1

41 How does your program determine its caseload management priorities?

I. Board reasons focusing on who made the decision, or how the decision was made:

1.	Staff input	24
2.	Governing board	14
3.	Client input	10
4.	Community input (citizen & advisory councils; public hearings, etc.)	
5.	Personal decision of attorney	6
6.	Project director	5
7.	Statutory mandate	4
8.	Annual meeting	3
9.	Service agency input	1
10.	State contract	1

II. Priorities seen as based on client needs and issues presented in their cases:

1.	Issue-orientated i.e. "all issues related to handicapped" "nursing home issues" "concentrate on issues affecting bare essentials of life" "affirmative class-wide law reform suits" "significance to other mentally retarded persons"	14
2.	Handle all requests	5
3.	Need of crisis basis	4
4.	Informal, ad hoc basis	3
5.	All facility residents	2
6.	Impact or import	2

42 Did that priority setting process take into account persons with mental disabilities? Yes 53 No 13

43 How?

1.	By the very nature of advocacy project and its relationship to disabled persons	15
2.	Personal choice or special interest of attorney in program	6
3.	Client input	5
4.	Statutory mandate	5

5.	Advocacy group contact	5
6.	Anticipated results and impact	4
7.	Included among general program priorities	4
8.	Community advisory group	2
9.	Staff input	2
10.	Decision of board composed of parents of mentally retarded children, representatives of Associations for Retarded Citizens, and service providers	1
11.	Through discussions and meetings	2
12.	Yes, "by excluding that class"	1
13.	Not present priority, but plan to include in the future	3

44	If not, why?	13 responses
	"No one advocated it"	2
	Not proposed as a concern	1
	No specific planning or interested/organized constituency	1
	Difficulty speaking for themselves	1
	Just starting on client input	1
	Understaffed - can not do outreach	1
	Not listed among 15 most pressing community problems	1
	Priorities set by types of cases	1
	No perceived demand	1
	No mental health speciality staff person	1
	Staff has not decided if it is important enough to assign numbers of staff to it required to do significant litigation	1

47 Would you be willing to take client referrals from national or state organizations?

Yes 75 No 9 Possibly 3

48 Are you interested in representing retarded persons in the future? Yes 69 No 3 Possibly 1

49 What kind of outside assistance would be helpful in providing legal advocacy for mentally retarded persons? (please give rank order)

		Rank Order					Check	Ranks & Checks
		1	2	3	4	5		Total
50	_______ a specialist back-up center	19	10	7	4	-	31	71
51	_______ resource materials	11	12	9	10	-	34	76
52	_______ training seminars	8	7	14	9	2	30	70
53	_______ consultation	4	12	9	12	2	28	67

54 __18__ other (please specify)

IF YOU ARE NOT INVOLVED IN LEGAL ADVOCACY FOR THE MENTALLY RETARDED, YOU MAY WISH TO STOP HERE, OR YOU MAY WISH TO RESPOND TO PART V ON FUTURE DIRECTIONS (see page 8) THANK YOU FOR YOUR RESPONSES TO THIS QUESTIONNAIRE.

IV. LEGAL SERVICES - PAST AND PRESENT

54-56 How many mentally retarded clients have you represented? _______________

57-60 How many other mentally disabled clients have you represented? _______________

61 Are you able to represent all such potential clients who seek your services? Yes __14__ No __46__

62 Are you able to represent all such potential clients who need your services? Yes __4__ No __55__

63-64 On the average, how many mentally retarded clients receive your services per month? _______________

65 If involved in individual representation, on the average, how many times do you see each client per case? _________

No. of times seen	
1	5
2	12
3	6
4	5
5-9	3
time varies	4
class actions	1

54 Other (please specify)

There were 18 respondents specifying other kinds of outside assistance.
Most frequently mentioned was receiving money (by 7 respondents) either in general or for some specific need.

Five asked for "experts" to act as witnesses, evaluation specialists, technical litigation and systems change advisors, etc.

IV. Legal Services - Past and Present

54- 56 How many mentally retarded clients have you represented?

# Clients

	1-4	5-9	10-19	20-49	50-99	100+	class actions
# people	10	5	5	7	4	8	22

Total for 52 respondents: 2927*

* The total number of mentally retarded clients represented was 2927 persons, an estimate which excludes mentally retarded persons represented as members of class actions.

57-60 How many other mentally disabled clients have you represented?

# Clients

0	1-4	5-9	10-19	20-49	50-99	100+	class actions
1	6	3	8	7	4	15	12

Total for 49 respondents: 4616*

* The total number of mentally disabled clients represented was 4316 persons, an estimate which excludes mentally disabled persons represented as members of class actions.

63-64 On the average, how many mentally retarded clients receive your services per month? ________________

0	1
1-4	25
5-9	2
10-19	5
20-49	9
50+	5
class actions	7

66-69 What is the average length of each initial client interview? ____________________

1/4 hour	2
1/2 hour	11
1/2 hour-59 minutes	8
1 hour	9
over 1 hour	3
it varies	2

70 In providing legal advocacy for the mentally retarded, how do you determine policy and priorities of case selection and methods of service?

The major difference in responses to this question centered around the fact that some groups made overt priority decisions while others seemed to see priorities implicitly set by the service offered or client demand. Groups who overtly formulated their own priorities generally answered by mentioning an issue-oriented or goal-oriented approach, or said they discussed their priorities with staff, advocacy groups, a board, etc. A number of other respondents indicated that their case loads are determined by client demands or the nature and constraints of their programs.

I. Priorities set by responding group	
A. Impact-oriented	17
B. Issue-oriented	7
C. Need-oriented	5
D. Respondents who answered by telling who helps set priorities	8
E. Personal decision	4
II. Priorities dictated by nature or constraint of program	
A. Time	3
B. Resources of program	4
C. Accept all clients or those sent by them, or all clients who qualify under their program	9
D. Client needs or characteristics	8
E. Statutory mandate	2

III.	Ad-hoc basis	1
IV.	Matching of clients needs and project priorities	1
V.	Priorities to be set in future	1

71 What, if any, are the stated goals of your advocacy efforts? *

* Note: Numbers to the right of each subdivision (indicated by a roman numeral) indicate the number of respondents to the category as a whole. Numbers to the right of subdivisions of each category are subtotals. The advocates listed multiple responses.

I.		Protection and Promotion of Rights of Disabled	21
II.		Habilitation Rights	11
	A.	Specific rights to disabled living in community and institutions	5
	1.	Right to treatment	1
	2.	Improved health care	1
	3.	Improved educational services	2
	4.	End misclassification through discriminatory evaluation procedures	1
	5.	Due process protection in civil commitment and guardianship, combatting labelling after institutionalization	2
	6.	Rights in community re housing and employment	1
	7.	Protection and safeguards re. hazardous/intrusive/experimental procedures	1
	8.	Right to confidentiality	1
	9.	Normalization to maximum feasible for mentally retarded in medical services, education, etc.	1
	10.	Support families rather than removing children	1
	B.	Specific rights to institutionalized disabled	7
	1.	Represent all clients with opportunity for release from institution	2
	2.	Ensure appropriate treatment/placement of institutionalized persons in least restrictive environment	4
	3.	Set up adequate checks on abuses	1
	4.	Improve institutional conditions	1
	5.	Implement recent patients' rights statutes	1

6. Proper services for MR residents in proper facilities	1
7. Conditions, treatment, civil rights in institutions	1
III. De-Institutionalization	4
A. Develop community facilities to aid process of de-institutionalization	1
B. Advised social service agencies regarding alternatives to institutionalization - especially alternatives to involuntary commitment	1
C. Community alternatives, zoning	1
IV. SSI	3
A. Improving SSI disability determination standards and their application	1
B. Represent and investigate cases of claimants for Social Security benefits - attempt to have client qualify and remain qualified	1
V. Community based efforts for disabled	7
A. Contact with disabled	3
1. Integration of disabled children into mainstream of society's human services	1
2. Better conditions of people living in independent living situations outside of institutions	1
3. Assist people with mental problems in finding and receiving needed services.	1
B. Contact with community groups of issues	4
1. Train citizen advocates	2
2. Back-up and support for advocacy groups	1
3. Speak before groups	1
4. Call plight of clients to public attention	1
5. Warn public of consequences from disregard of the problem, and its cost to the public	1
VI. Other activities of benefit to develop disabled	6

A.	Alleviate problems through negotiation and administrative mechanisms	1
B.	Educate courts on issues never raised in commitment hearings	1
C.	More funding for mental health services	1
D.	Technical assistance in drafting legislation	1
E.	Enforcement of outstanding decree requirement and constitutional, statutory and regulatory demands	1
F.	Educational services	2
G.	Law reform efforts	2
VII.	Goals not specifically related to disabled	8
A.	Disabled as part of broader client community	4
1.	Indigent	2
2.	Children	2
B.	General law reform work	3
1.	Class action law reform litigation	1
2.	Litigation with a systems approach	1
3.	Implementation of statutory mandate to represent institutionalized disabled	1
C.	General client representation	4
1.	Protect rights/represent clients	2
2.	Achieve what client wants or if non-communicative - what is in best interest of client	1
D.	To educate public as to rights of mentally retarded persons	1

66-69 What is the average length of each initial client interview? ____________________

70 In providing legal advocacy for the mentally retarded, how do you determine policy and priorities of case selection and methods of service? ____________

____

____

71 What, if any, are the stated goals of your advocacy efforts? ____________________

____

____

What advocacy methods do you use? (check all that apply)

1	44	case work
2	59	negotiation
3	56	litigation
4	57	referral
5	24	training consumers as self-advocates
6	27	attending case conferences
7	48	administrative hearings
8	37	monitoring
9	44	legislative advocacy
10	25	outreach
11	36	community education
12	34	back-up assistance
13	31	training others
14	25	manual writing
15	42	group representation
16	16	investigative reports
17	36	participation in rule or regulation-making

processes

18	37	forwarding human rights complaints to appropriate agencies
19	41	efforts to implement new laws or major decrees
20	46	work to reform institution/agencies affecting clients
21	______	Other - please specify

22-26 Which methods used have been most successful? ____________

____

____

____

27-31 Which methods used have been least successful? ____________

____

____

____

If litigation has been used, please indicate the type(s) and citations to any reported cases (check all that apply)

32	45	individual representation
33	36	civil commitment
34	23	other admission challenges
35	32	test cases
36	42	class actions
37	41	Federal constitutional claims
38	29	Federal statutory claims
39	22	State constitutional claims
40	39	State statutory claims
41	______	Other - please specify

22-26 Which methods used have been most successful? ______________

____

____

____

Litigation	31
Negotiation	19
Legislative advocacy	11
Administrative hearings	7
Participation in rule or regulation-making process	7
Monitoring	5
Efforts to implement new laws or major decrees	5
Case work	4
Attending case conferences	3
Training	3
Outreach	2
Community education	2
Back-up assistance	2
Manual writing	2
Group representation	2

27-31 Which methods used have been least successful? ______________

____

____

____

Forwarding human rights complaints to appropriate agencies	8
Litigation	7
Negotiation	6
Legislative advocacy	6
Monitoring	4
Participation in rule or regulation-making processes	4
Referral	3
Work to reform institutions/agencies affecting clients	3
Attending case conferences	2
Administrative hearings	2
Outreach	2
Community education	2
Back-up assistance	2
Manual writing	2

Q. 42-46 p. 6

What have been some of the advantages of using the type of litigation selected?

I. Responses mentioning a specific result of particular cases or kind of litigation.

A. Affirmative Enforcement 14

"Pressure of order causes changes"
"Some court orders obeyed"
Enforcement of statutory and constitutional mandate
Produce change that transcends staff personalities
Effective in results
Winning cases for clients
Possibility of greater system-wide change
High impact
Get a response
Law Reform
Breaks up logjams
Show of brute force,
Great impact
Individual litigation almost always results in success for the client. The system is more responsive to individual cases.

B. Speedy Remedy 2

"Rapid remedies"
Direct, immediate and mainly correct results

C. Class Impact 5

A feeling and a reality that you can solve a problem for more than just one person
Affects all patients at an institution
Favorable decision immediately benefits large numbers of similarly situated persons
Affects whole class
Class suits testing state laws in state courts with federal statutory and constitutional claims have proven very successful in resolving problems in Michigan

D. Results for Specific Clients 8

Class action has protected money of residents both at the MR and MD facilities from being returned to the state general fund pending resolution
Statewide moratorium on institutional construction
Release on residents
Successful "test case" can lead to change in admini-

strative processes and similarly, stimulate legislative change given appropriate follow-up.
Judicial review of institutionalization
Hold off Bureau of Support from collecting from clients
Filed habeas - got release before trial

II. Indirect Advantages of Litigation

A. Attention Getting Device 8

Public attention
Court attention
Class action-most attention getting and effective
Press attention to previously unreported issues
Heightened attention to problems
Focus attention on a problem and get a response
Attracts high quality experts

B. Awareness 7

Awareness of individual rights
One major class action has resulted in dramatic consumer awareness
Consciousness raising
Rally point for advocates
High profile
Excellent means of gathering information for distribution to consumer and legislature
Community support

C. Leverage/Pressure 4

Impressing clinical staff with legal claims
The Rainey class action - leverage for funding
Litigation pressure permits greater control of results

D. Mobilization 1

Mobilizing resources (economic/political) to improve plight of mentally disabled

E. Efficiency 1

Most impact as to available time and resources

F. Negotiation/Action 3

Negotiation easier once suit is filed
Strengthens negotiation positions
Forces a recalcitrant state bureaucracy to move on issues even if there is no final judgment entered but simply a negotiated settlement

G.	Precedent to benefit future clients	1
H.	Varies	4

Marked variation depending on court
Depends on judge and defendant's counsel in thwarting decent settlements and implementation
Varies with issue attacked

47-50

What have been some of the pitfalls? (of type of litigation selected)

I. Specific problems of type of litigation selected

A. Unsuccessful Outcome 5

Failure by judiciary to actively protect and promote the rights of the developmentally disabled
Losing cases-set bad precedent
If unfavorable decision, substantial resources over considerable time have been expended to no positive end.

B. Unresponsive Judicial Attitudes 2

Federal courts less accessible due to liberal application of the conservative federal abstention doctrine
Probate court unreceptive to reform
State court litigation of any issue pertaining to civil rights runs into judicial deference to status quo and dependent agencies

C. Lack of Enforcement 10

Problems of enforcement
Implementation and enforcement of judicial decrees and/or consent orders
Major difficulty of achieving implementation of decree when it calls for major change in social service delivery system, as most cases do
Monitoring almost possible with present level of resources
State lack of resources leads to judicial restraint in drafting remedies.
Does not provide needed alternatives to institutionalization
If a case involves illegal patterns and practices, enforcement problems in changing "whole" system, even when successful on claims
Implementation difficulties if class action test cases.
"can't make competents out of incompetents" (administrators)

D. Mootness 3

Mootness in systemic issues
Mootness upon patient release or escape
Procedural problems bog down litigation till patient released-unfavorable mootness rulings result

II. Broader Problems

A. Time 11

Wasted work (until we learned how to do it)
Takes too long
Protracted litigation-find outcomes murky
Slowness
Scope of litigation/time/effects on ability to assume individual representation
Appeals on mental health commitments (even considering this is a rural state) are taking more than a year to get decisions in the state Supreme Ct. while the residents remain committed

B. Resources 5

Expenditure of large sums of money that could have been better used
Protection and advocacy service, though good, needs far more capacity to handle the job of individual litigation
Costs of all litigation
Extensive dislocation of program resources to the neglect of other areas
Lack of manpower to class actions

C. Pyrrhic victories 2

Achieving only procedural rather than substantive victories
Individual cases usually do not result in system-wide change. On the other hand, class action litigation does not hold promise for effecting actual change, even though good court orders are obtained. Litigation may not be effective way of obtaining system-wide change

D. Procedural Obstacles 2

Resistance to class action-refusal of discovery of class members records
Litigation for mentally disabled runs into endless procedural problems

E. "Freeze-Outs" 2

Terrifying institutional staff, thereby prejudicing negotiation in behalf of other clients
Closing potential sources of discovery of institutional information

42-46 What have been some of the advantages of using the type of litigation selected? ______________________

____

____

____

47-50 What have been some of the pitfalls? ______________________

____

____

____

In what subject matters have you engaged in legal advocacy for the mentally disabled? (please specify type of issue)

51	44	Institutional conditions and practices
52	39	Deinstitutionalization
53	38	Civil commitment
54	32	Inmate/resident grievances
55	37	Education
56	17	Housing and Zoning
57	18	Employment
58	36	Treatment/Habilitation Issues
59	13	Access to Physical Facilities
60	19	Discrimination in Civil Rights
61	40	SSI and other welfare benefits
62	19	Custody Cases
63	29	Guardianship
64	23	Correctional/criminal
65	28	general legal problems
66		other - please specify

How does your program obtain clients? (check all that apply)

67	57	referral (types of sources)
68	42	walk-in
69	17	court appointment
70	15	office in institution
71	13	advertising
72	7	hot-line
73	35	public contacts
74	21	walking wards/visiting facilities
75	31	consumer groups liaison
76	11	grant of statutory or contractual authority
77		other - please specify

If you are involved in client outreach efforts, what methods do you use?

1	30	public speaking
2	15	newspapers
3	12	TV/radio public announcements
4	7	other media efforts
5	33	ties to consumer organizatons
6	21	community organizations/educational coordinators
7	17	non-legal professional (please specify)
8	6	representation by "next friends"

From what consumer categories are the majority of your clients? (check as many as appropriate)

9	39	institution/hospital based
10	46	indigent
11	24	commitment process

12 34 mentally retarded

13 30 mentally ill

14 20 juveniles

15 18 developmentally disabled

16 3 alcoholic

17 10 physical disabled

18 ______ other - please indicate

V. FUTURE DIRECTIONS OF LEGAL SERVICES

What subject matters do you feel should receive high future priority attention?

19 44 Institutional conditions and practices

20 57 Deinstitutionalization

21 26 Civil commitment

22 22 Inmate/resident grievances

23 36 Education

24 36 Housing and Zoning

25 36 Employment

26 42 Treatment/Habilitation Issues

27 11 Access to Physical Facilities

28 19 Discrimination in Civil Rights

29 26 SSI and other welfare benefits

30 6 Custody Cases

31 19 Correctional/criminal

32 19 Guardianship

33 14 general legal problems

34 8 other - please specify

With respect to the mentally retarded persons, what litigation methods or legal theories do you think should be tested or should be more frequently used?

35 24 individual representation

36 10 civil commitment

37 11 other admission challenges

38 24 test cases

39 31 class actions

40 31 Federal constitutional claims

41 31 Federal statutory claims

42 24 State constitutional claims

43 26 State statutory claims

44 5 Other - please specify

What respect to mentally retarded persons, what advocacy methods do you think should be tested, or should be more frequently used?

45 17 case work

46 22 negotiation

47 31 litigation

48 6 referral

49 25 training consumers as self-advocates

50 7 attending case conferences

51 25 administrative hearings

52 27 monitoring

53 37 legislative advocacy

54 15 outreach

55 24 community education

56 18 back-up assistance

57 15 training others

58 11 manual writing

59 20 group representation

60 11 investigative reports

61 24 participation in rule or regulation-making processes

62 7 forwarding human rights complaints to appropriate agencies

63 28 efforts to implement new laws or major decrees

64 26 work to reform institutions/agencies affecting clients

65 10 other - please specify

66 Do you feel that Legal Services Corporation and local programs can or should do more in this area of legal assistance?

Yes - 63

No - 2

67 How?

68 Do you feel that the legal profession and Bar groups generally can or should do more in this area of legal assistance?

Yes - 38

No - 10

69 How?

70-73

Q. 66-67 p.10

Do you feel the Legal Services Corporation and local programs can or should do more in this area of legal assistance?

Yes - 63 No - 2 No response - 31

How?

Types of Responses

Need for L.S.C. to establish special centers or projects focusing on the developmentally disabled - it was frequently mentioned that funding is necessary to do this.

Selected Comments:

a) Specialized projects or centers should fund through a specially designed program with mental health and DD Law Projects in various states

In urban areas where a sufficient number of cases are presented - organize specialty offices (analogous to P.D. offices) since this is a specialized areas of practice

Probably should develop special projects or units to attempt to take advantage of developing resources (i.e. special education under P.I. 94-142)

Depending upon community served, special projects in this area should be developed in cooperation with other community groups and the L.S.C. should develop the capacity to support such projects

Funds specialty programs (like this one)

Establish more resource centers staffed by persons with not only litigative skills but expertise in programmatic matters such as restraint and seclusion and psychotropic drug use alternatives to which practitioners may turn

LSC should provide location for services on regional basis

Special projects: see Yale Law School civil commitment/mental health project

b) Need for specialized staff:
Each major program should have MR-MH specialist - The area is too specialized for the average staff member to adequately handle

Encourage local offices to have one or more people responsible for addressing these issues

c) LSC should make representation of mentally disabled a priority
Should include programs for mentally disabled in priority setting - no one to speak for this client group

Higher priorities

Make representation of mentally retarded persons a priority

More representation but that includes priorities of program

I agree with suggestion for specific mandate to serve mentally retarded otherwise rights of mentally retarded get lost in large caselads, etc. of legal services. The more articulate members of client community get the services - outreach into institutions absolutely essential

Need for legal services to represent the developmentally disabled and mentally ill
This requires special funding

Encourage and back-up Public Defenders in more effective representation in commitment processes and in criminal correction process

d) Special kinds of action LSC should undertake

1. Litigation:

   Mostly litigation
   Litigation
   Law reform

   Coordinate nationally ongoing litigation

2. Test cases:

   Caseload management is a constant problem-test case reform as approach to actual casework would have longer effect

   Class action suit re zoning, right to treatment, education

3. Representation of individuals:

   By providing greater services to those individuals in the "class" population

   Extend personal legal services to mentally retarded citizens

   Determine how to get access to persons really incompetent to consent to representation or anything else

4. Representation of institutionalized

   Fund existing and new programs to provide legal services to institutionalized individuals

Creation of more in-institution programs to provide legal services to institutionalized individuals

Grants should be available from Corporation for institutional services (conflict of interest when money is received from State Department of Institutions)

5. Legislative advocacy:

   By federal legislation or by regulation

   Law reform

6. Other suggestions:

   Administrative advocacy:
   e.g. in the SSI program, relevant to hearing processes set up locally under recent federal legislation and regulations for the handicapped

   Support research on these issues

   Organize state bar group. Sponsor state conferences on legal representation of mentally retarded and devlopmentally disabled for attorneys in private practice, do it through Continuing Legal Eduation and state law schools

   Lobbying for federal advocacy programs (i.e. DDA)

   Appoint retarded people and/or their advocates to Legal Services Board of Directors at local level

   Should encourage or require grantees to demonstrate affirmative action for the mentally handicapped

   Do more non-litigative work

Service desired by Respondents

Outreach

Outreach and intake at institutions

Outreach, some percentage of effort

Outreach visits to institutions; contact with health care workers

Staff development

Increased number of attorneys, paralegals, and all office personnel will be needed

Paralegals - train ARC volunteers and staff trained advocates

More people (we have 1 attorney and 1 paralegal for institutional population of 3,500)

Need lawyers to handle cases for developmentally disabled, including number of advocates

Volume of requests especially from institutions too great for few people in area

Back-up

Establish mental health back-up

Better access to national back-up centers

Back-up center established by corporaton

It has been my finding that most local legal services offices have been willing to forego representation of the mentally disabled persons if there is any kind of advocacy office in the area whose primary purpose is such representation. I think this attitude must be reversed. I think a national back-up is as important in this area as in any other of law.

Richly funded back-up center

National resources center for the mentally disabled

Training

Training of other lawyers

Train lawyers better on issues

New developmental disabilities project advocates should attend seminars and training sessions in near future

Primarily through some intensive training and development into national legal network, however that might be done

Training seminars for attorneys-training information - dissemination

Funding & Resources

Only those who made funding a central issue in their answers are listed here. Many respondents in discussing particular programs or goals they wanted to see realized, mentioned funding peripherally and were not counted in this category. More general discussions of "resources" or "materials" are listed at the end of this section.

Utilize some of the LSC funds for developmentally disabled

Submit proposals for developmentally disabled

More staff and funds in order to do adequately the discovery, depositions, and other trial preparation procedures that need to be done

Funds for lawyers doing developmental disabled work for test cases, class action and working with consumer agencies to improve state legislation

For representation of mentally disabled including establishment of back-up center

Encourage allocation of resource through use of special needs funding

A special percentage of resources say 10-15% should be directed towards meeting the legal needs of developmentally disabled clients

Increased awareness

More education of themselves so as to be more aware of these problems

Including staff awareness of the causes/prevention of mentally retarded and the needs/rights of mentally retarded people

By awareness of currently developing statutes and constitutional rights to services to which handicapped individuals are entitled and reference to agency which will represent handicapped client if not actual representation

Make community aware of legal rights for handicapped - rural areas which my office serves, are particularly ignorant of new developments in the law

Investigative reporting

Mass public relations drive-to bring to public's attention problems of mentally ill

Monitoring

Community Services

Work for more and better services in the community

Consultation

Those responding "No"

Legal profession may not be able to do more in areas - given specialized nature of pratice - large amount of time necessary to become knowledgeable. Economics of law practice discourage participation

Legal services programs and LSC could do more only at sacrifice of indigent cases on behalf of indigent persons. Funding levels for indigent inadequate. Bar Association efforts may be effective - since work for disabled lack political overtones.

Q. 68 & 69 p. 11

Do you feel the legal profession and Bar groups generally can or should do more in this area of legal assistance?

Yes - 38 No - 10 No Response -26

How?

Selected Comments:

Pro Bono Activity or other donation

The Bar or independent lawyers might donate large blocs of time to a mentally retarded program or donate legal services attorney salary for one year

Donating time and resources to indigent and class representation

Community oriented conceptions of what Bar should do

I believe the Bar should work towards creating an experienced mental health bar, through training and special funding, otherwise the mentally disabled will remain underrespresented as well as poorly represented

Integration of Private Bar and P & A system, L.S.C. in common goal findings, role playing and strategy planning to avoid duplication

Establishment of bar committees to work with and assist full time LSC lawyers - research - handle individual court cases, etc.

By specifically allocating funds for representation of mentally disabled, including establishment of back-up center, by lobbying for federal advocacy program (i.e. DDA)

Organize bar-sponsored state conference on legal representation of mentally retarded/developmentally disabled for participation by attorneys in private practice-do it through continuing legal education programs, and state law school and Inst. of Government. We need to show them that legal problems of mentally retarded have so much similarity with legal problems of other under/unrepresented minorities - the "Bar" is ignorant of the mentally retarded population and not generally willing to serve them

Seek attorney's fees under Civil Rights Attorney's Fees Award Act of 1976 to set up programs for attorneys and law firms to donate percentage of time

On all levels - individual cases, test cases, back-up training of other lawyers, preparation of materials

Establish active Committees at state and local level

Legal assistance for retarded people must be done in close conjunction with professionals who are committed to the concepts of normalization and least restrictive setting choices so that alternatives are properly designed. The availability of such expertise is indeed limited, and thought should be given to mechanism by which such services can be made more accessible.

Fund public interest groups, develop special bar projects

Private funds-public interest groups

Lawyer training

Encouraging funds for legal advocacy programs so that attorneys can be employed in these areas

The legal profession could support broad public interest advocacy in the mental disability field through financial aid to local or bar-sponsored public interest firms or projects (referrals to volunteer panels will probably never work)

Education

Offering courses in law school dealing with the problems so that law students are made aware of this area of law and perhaps would enter this area of practice - hold seminars and small meetings to discuss this field

Helping to educate other lawyers and the judiciary - sensitizing

The bar should be educated by mental retardation law specialists to do the potentially lucrative representation, e.g. special education hearings

Need for exposure of law students to needs of this group of persons. Attempt to develop ways of incorporating materials into continuing education programs for lawyers and judges. Bar Association Committees should be established to develop a core of interested lawyers

By recognizing the special problems of the retarded and establishing more programs like LSC to educate and motivate the members of Bar

Legislative Advocacy

Legislative and regulatory processes might respond to (effective) pressures from the Bar. The bar might also have a role in community education.

Appointment of private members of the Bar for representation - legislation changes

By contributing funds, supportive expertise and legislative lobbying to support programs and legislative change

We are attempting to develop a statewide referral mechanism to support efforts of legal service offices. Bar can lead in legislative efforts and non-litigative efforts, such as access, monitoring, etc.

Lobbying

Bar group can be especially helpful on legislative advocacy since they add respectability

Miscellaneous

Specifically in administrative hearings and civil rights complaints to administrative agencies

The free legal service agencies in this area will not represent individuals in SSI, SSD, welfare appeals. I think the need in this is tremendous. There needs to be much more sensitivity by the legal profession to the special needs and interpersonal requirements to mentally ill people.

Often, people with special education problems have the capability of paying lawyers. Some expertise could be developed by selected members of the private Bar.

They could do a better job on civil commitments. Representation by private Bar is often pro forma in that type of case.

They could provide a balancing force on behalf of the criminal offenders to show that the offender as well as the prosecutor has a side. We have a very recent issue where the county attorneys are propagandizing the public that the hospital is releasing criminal offenders or in essence misrepresenting to judges the condition of persons to be released. Obviously in our state system judges have the key since they must approve release of criminal offenders. The offenders are underrepresented. The courts, county attorneys and defenders very often ignore their due process rights, often they're recommitted. Somehow the Bar should provide forums to educate the public in these matters.

Skeptical and/or negative responses

They should obviously, but I do not foresee significant assistance from them until there is better understanding of mental retardation and/or more money in it for lawyers.

I say no, because bar groups and private attorneys rarely are willing to spend the time to consult with consumers or master the complex areas of law and social science necessary to adequately represent mentally disabled persons.

The private Bar in Kansas does not respond to this area of the law.

I think they should, but I do not believe the private Bar will ever provide sufficient amounts of, or quality of legal representation to the mentally disabled.

APPENDIX B

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RESPONDENTS TO QUESTIONNAIRE

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